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 19, January 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).

HAPPY NEW YEAR!

We would like to take this opportunity of wishing all our readers around the world a Happy, Healthy & Peaceful New Year 2010.

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

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

220 delegates from 18 countries descended on Nantes in December 2009 to attend Convergences PP. This was a unique, bilingual, multidisciplinary conference on pelviperineal pain co-organised by SIFUD, AFU, CNGOF, PUGO/IASP, SCGP, SFETD, SIREPP, SNFCP and SOFMER at the International Congress Centre of Nantes in France. Special thanks are due to Dr JJ Labat, congress president, and Professor R. Robert, Honorary President, from Nantes and the organizing and scientific committees for their hard work in getting this interesting and important meeting off the ground. For those who missed it, it is hoped to organize this conference every two years with the next one in 2011.
Several patient organizations working in this field were represented here, including the IPBF (Jane Meijlink, chairman), Association Française de la Cystite Interstitielle (Françoise Watel, president), Pelvic Pain Support Network, UK (Judy Birch) as well as representatives from the Association Française d'Algies Périnéales & Névralgies Pudendales, kindly provided with complimentary info tables for their patient support

groups by the organizers. The IPBF would like to express its grateful thanks to Dr Labat for giving us this opportunity.
The conference began on 16 December with 5 workshops, three of which were in French only and two in English only. Since the workshops were given twice, delegates could choose to attend two. The remaining two presentation-packed days were bilingual with simultaneous translation. Speakers included many well-known experts in the field from France and abroad. A review can be found on our website at: http://www.painful-bladder.org/pdf/2009_Convergences%20PP_Nantes.pdf

UPCOMING CONFERENCES AND EVENTS:

NIH/NIDDK SYMPOSIUM ON NEUROIMAGING IN UROLOGIC PELVIC PAIN AND ASSOCIATED DISORDERS HAS BEEN POSTPONED

Please note that the NIDDK has informed us that the NIH/NIDDK symposium on "Neuroimaging in Urologic Pelvic Pain and Associated Disorders" tentatively planned for March 2010 has now been postponed until later in the year. We will provide you with further information and a date when available. The NIDDK will publish details when available on their website: http://www2.niddk.nih.gov/ (go to "Conferences and Workshops" bottom left of home page).

P.U.R.E. H.O.P.E. (PELVIC & UROLOGICAL RESOURCES & EDUCATION) 2010 ANNUAL PELVIC HEALTH PATIENT EDUCATION DAY CONFERENCE

The 5th Annual Pelvic Health Patient Education day conference organised by P.U.R.E. H.O.P.E. will be held on Saturday, 20 February, 2010, 7:30 a.m. to 4:30 p.m. (Registration 7:30 – 8:30 a.m.) at Crowne Plaza GreensPoint, 425 North Sam Houston Pkwy E, Houston, TX 77060, USA. There will be a Meet the Speakers Reception on Friday, 19 February, 2010, 4:30 p.m. – 6:30 p.m. The low $40.00 registration fee covers admission to the "Meet the Speakers Reception" on Friday, the "Patient Conference" on Saturday, information packets, breakfast, extra special lunch & drinks. P.U.R.E. H.O.P.E. president Cindy Sinclair tells us that this 5th Annual Conference will be much bigger than all the previous conference. They will have 10 speakers, 4 in the general session and 6 in two breakout sessions. There will also be round table discussions at lunch.
Registration can be done via the website www.pure-hope.org.

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/showarticle.pl?id=1006;n=605

VITH INTERNATIONAL CONFERENCE ON RARE DISEASES AND ORPHAN DRUGS (ICORD 2010) "GLOBAL ACCESSIBILITY AND NEGLECTED DISEASES", 18-20 MARCH 2010, ACADEMIA NACIONAL DE MEDICINA, BUENOS AIRES, ARGENTINA.

A global meeting on international cooperation and policies for rare diseases and orphan products will be held in Buenos Aires, Argentina on March 18-20, 2010. The VI International Conference on Rare Diseases and Orphan Drugs (ICORD 2010) for the first time will be convened in the southern hemisphere in agreement with its aim of globalization of rare diseases research and orphan products development activities. Individuals and organizations from patient groups, academic research investigators, the pharmaceutical, biotechnology and medical device industries, and government policy and decision makers are invited to participate in this unique forum. Specialized courses, and open meetings with key people in the field will be available for participation during the preceding days (March 16 and 17), as well as an opportunity to discuss and learn about Latin American and Caribbean initiatives.
The meeting will be hosted by the GEISER Foundation, the first non profit umbrella organization for rare diseases in Latin America & Caribbean. For further information, please contact fundgeiser@yahoo.com.ar or the GEISER Foundation website http://www.fundaciongeiser.org and www.icord2010buenosaires.net .

5TH EUROPEAN CONFERENCE ON RARE DISEASES ECRD 2010

The 5th European Conference on Rare Diseases ECRD 2010 will be held in Krakow, Poland on May 13-15, 2010 around the theme “From policies to effective services for patients”. This conference will look at national plans and strategies for rare diseases, European reference networks and centres of expertise, information and medical education, science from bench to bedside, rare diseases in Central and Eastern Europe, and much more. Further information on this conference may be obtained from: http://www.rare-diseases.eu/2010/index.php.

ESSIC ANNUAL MEETING 2010

The European Society for the Study of IC/PBS (ESSIC) will be holding its 2010 annual conference in Antwerp, Belgium, Thursday 20 to Saturday 22 May 2010. This year all scientific presentations will be open to all registered delegates.
On Thursday afternoon, special attention will be paid to the topic of fatigue. The programme on Friday will include presentations on questionnaires and symptom scores, on the (patho)physiology of the bladder and a session on scientific presentations/abstracts submitted. Deadline for submission of abstracts is 1 May 2010
On the Saturday morning, educational courses will be given in English on the clinical picture, diagnosis (including confusable diseases and associated disorders), treatment (oral, intravesical, surgical etc). On the Saturday afternoon, an educational programme will be given in Flemish/Dutch for local clinicians.

Registration and venue details will be available shortly on the ESSIC website: www.essic.eu.

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 which will be held 29 August-2 September 2010.
The objectives 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

PATIENT ORGANISATIONS & WEBSITES

GREEK WEBSITE: CENTER FOR UROLOGIC AND PELVIC PAIN

The Center for Urologic and Pelvic Pain in Greece has a website http://www.cppc.gr in Greek and English. Details of the organization are as follows:
Contact person: Konstantinos Kalyvas, Urologist
Chalkidikis 51-Building A2
GR 555 35
Pilea-Thessaloniki, GREECE
Tel - Fax 0030 2310 324020
Mobile phone 0030 6944 836815
email kalyvas@cppc.gr

CHANGE OF ADDRESS COB FOUNDATION, UK

Please note that the Cystitis & Overactive Bladder Foundation in the United Kingdom has moved to a new address as follows:
Cystitis & Overactive Bladder Foundation
Chair: Dawn Baty
Kings Court
17 School Road
Birmingham B28 8JG
tel: +44-(0)121-7020820
email: info@cobfoundation.org
www.cobfoundation.org

FRENCH ORGANISATION FOR PERINEAL PAIN AND PUDENDAL NEURALGIA ASSOCIATION FRANCAISE D'ALGIES PERINEALES & NEVRALGIES PUDENDALES (AFAP-NP)

This French-language association (president Marie Boutet), for patients with perineal pain and pudendal neuralgia, works closely with the AFCI, the French IC support group chaired by Francoise Watel. This AFAP-NP French website will be of interest to French speakers in different parts of the world.

Details of the association are as follows:

Association Francaise d'Algies Perineales & Nevralgies Pudendales (AFAP-NP)
President: Marie Boutet
60 rue Truffaut
75017 Paris, France
email: contact@afap-np.com
www.afap-np.com

THERAPY IN THE PIPELINE

NEW SLOW RELEASE LIDOCAINE TREATMENT UNDER DEVELOPMENT LIDOCAINE-RELEASING INTRAVESICAL SYSTEM

Taris Biomedical, based in the USA, has developed an innovative drug delivery system for IC/PBS described as a drug-device convergence product. It consists of two main components: a drug and a retentive device and primarily provides a controlled release of the drug (lidocaine) in the bladder over a period of weeks. The system is called the lidocaine-released intravesical system or LiRIS. It is designed to be inserted into the bladder via cystoscopy or catheter and when empty the device can be removed again by cystoscopy. Further information may be obtained from: http://www.tarisbiomedical.com/technology.php.

WEBSITE: CATHETER-ASSOCIATED URINARY TRACT INFECTION PREVENTION CENTER.

UroToday.com has announced the launch of The Catheter-Associated Urinary Tract Infection Prevention Center. UroToday.com developed this resource centre in collaboration with Verathon Inc. in order to support awareness of infection prevention protocols and provide resources for healthcare professionals in the prevention of catheter-associated urinary tract infections (CA-UTIs).

See UroToday press release:
http://www.urotoday.com/index.php?option=com_content&task=view_ua&id=2226701
See CAUTI Center:
http://www.urotoday.com/cauti_center/index.html

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. 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 and/or combinations of these. When reviewing the article, we generally use the terminology used by the authors.

PSYCHOSOCIAL PHENOTYPING IN WOMEN WITH INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME: A CASE-CONTROL STUDY.

Nickel JC, Tripp DA, Pontari M, Moldwin R, Mayer R, Carr LK, Doggweiler R, Yang CC, Mishra N, Nordling J. J Urol. 2010 Jan;183(1):167-72. [Epub 2009 Nov 12]. PMID: 19913812

The clinically validated UPOINT clinical phenotyping classification system has indicated that phenotypes expressed outside the bladder (P = psychosocial and N = neurological/systemic) have the most significant impact on quality of life. The purpose of this multi-centre study by Nickel and colleagues was to characterize and compare psychosocial phenotypes in a group of female IC/PBS patients and a matched control group. Questionnaires were completed by 207 IC/PBS patients and compared with those of 117 matched controls. IC/PBS patients reported for example: greater pain and worse quality of life, significant sleep dysfunction, depression, anxiety, stress sexual dysfunction and a greater perception of lower social support than the control group. The authors suggest further analysis of the impact of sleep dysfunction on IC/PBS symptoms and quality of life. The authors conclude that IC/PBS patients have significant psychosocial changes compared to controls which need evaluating and managing by their clinician.

LIFE IMPACT OF UROLOGIC PAIN SYNDROMES.

Hatchett L, Fitzgerald MP, Potts J, Winder A, Mickelberg K, Barrell T, Kusek JW; Urologic Pelvic Pain Collaborative Research Network. Collaborators (35) Fitzgerald C, Badillo S, Neville CE, Marko D, Potts J, O'Dougherty E, Murphy D, Peters K, Odabachian LK, Sanfield A, Anton E, Fitzgerald MP, Kotarinos RK, Fortman C, Halle-Podell R, Senka J, Rindels J, Raducanu L, Anderson RU, Cosby A, Morey A, Payne CK, Fraser LC, Clay D, Ramakrishnan A, Clemens JQ, Landis JR, Mickelberg K, Durborow M, Barrell T, Chuai S, Cen L, Kusek JW, Nyberg LM, Mullins C. J Health Psychol. 2009 Sep;14(6):741-50.PMID: 19687111

The object of this small but multi-centre study was to explore patients' (23 male and 24 female) personal experience of chronic urologic pain in journal form. The study team therefore invited patients to write down in their own words their daily symptoms and the effects of those symptoms on home/family life, working life and social life since exploring the perspectives of patients may provide unique insights and suggest directions for clinical practice and research.
The authors explain that "the basic premise of this approach is to generate theory from data rather than impose a pre-existing theory or model".
The journals revealed three main themes: physical health, emotional health and role limitations/social health. In the field of physical health, it was interesting that 15 patients stressed the symptom of fatigue. This is a symptom that has not hitherto been considered part of the IUCCPS syndromes but that merits further attention. The authors suggest that "UCPPS studies may benefit from renewed focus on life impact and from further exploration of symptoms, mediators and role limitations that disrupt our patients' daily lives".

ENDOSCOPIC ABLATION OF HUNNER'S LESIONS IN INTERSTITIAL CYSTITIS PATIENTS.

Payne RA, O'Connor RC, Kressin M, Guralnick ML. Can Urol Assoc J. 2009 Dec;3(6):473-7. Can Urol Assoc J. 2009 Dec;3(6):473-7. PMID: 20019976

Free access to this article: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2792435/?tool=pubmed

The authors report retrospectively on their experience with endoscopic ablation of Hunner's lesions in 14 women with IC in the age range 28 to 85. “Ablation” comprised either fulguration with a Bugbee electrode or resection with a loop cautery, depending on the surgeon’s preference. In this group of patients, office cystoscopy with local anaesthesia (lidocaine gel) was performed without hydrodistension during which the lesions could be identified, followed at a later date by cystoscopy, biopsy and ablation under general anaesthesia. Irrigation fluid in the cystoscopy was limited to 200 ml with the irrigation bag kept below 50 cm height. During the first office cystoscopy, the authors note that they “considered any erythematous lesion as a potential Hunner’s lesion if touching the lesion with the cystoscope reproduced the patient’s symptoms (pain, urgency) and touching benign-appearing areas of urothelium did not.” They describe the lesions as often having “small vessels radiating towards a central area of pallor…, sometimes associated with a fibrinous exudate”. Subsequent fulguration or resection of the lesions under general anaesthesia led to an improvement in symptoms. If the symptoms recur after a period of time, the authors suggest that cystoscopy should be carried out again to check for more lesions and if present ablation can be repeated. Two patients reported no change in their symptoms (one of whom was shown by biopsy to have venous angioma), while the remaining 12 reported at least a 50% improvement and even complete resolution (7 patients). There were no complications as a result of this endoscopic ablation. They emphasize that any bladder lesion should always be biopsied to exclude bladder cancer. The authors conclude that cystoscopy is important to diagnose lesions and that endoscopic ablation of lesions improves symptoms in most IC patients, including those who have failed many previous therapies and that it could be considered a first-line treatment for patients with Hunner’s lesion.

BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS: A SENSE OF URGENCY

Hanno PM, Chapple CR, Cardozo LD. World J Urol 2009;27:717-21. PMID: 19551386

A review of BPS/PBS/IC in the World Journal of Urology with emphasis on definitions and terminology, with a special look at urgency and differences between overactive bladder and BPS/PBS/IC. Regarding the latter, the authors suggest that differences in the other primary symptoms probably have an influence on how the patient perceives urgency. The authors consider that advances in research into the pathophysiothology of urgency and underlying disease processes will help to optimize both diagnosis and treatment of BPS/PBS/IC.

BLADDER OUTLET OBSTRUCTION IN PAINFUL BLADDER SYNDROME/INTERSTITIAL CYSTITIS.

Cameron AP, Gajewski JB. Neurourol Urodyn. 2009;28(8):944-8.PMID: 19301413

This is a retrospective study of 231 patients based on the hypothesis that some PBS/IC patients have an associated measurable bladder outlet obstruction (BOO) secondary to dysfunctional voiding and that patients with more severe PBS/IC with lesions are more likely to have BOO and worse urinary symptoms. 193 pts in the study had non-ulcer PBS/IC and 38 had the Hunner’s ulcer (lesion) variant. The authors found that 48% of their PBS/IC patients did indeed have an element of obstructive voiding on urodynamic investigation and concluded that increasing severity of PBS/IC is associated with higher voiding pressure. The authors are of the opinion that this obstruction is due to dysfunctional voiding and not either structure

disease or other anatomical obstruction and postulate that pelvic floor spasm secondary to painful voiding may be the cause of the obstruction.

INTRAVESICAL INSTILLATION OF HYALURONIC ACID PROLONGED THE EFFECT OF BLADDER HYDRODISTENTION IN PATIENTS WITH SEVERE INTERSTITIAL CYSTITIS.

Shao Y, Shen ZJ, Rui WB, Zhou WL. Urology. 2009 Dec 16. [Epub ahead of print]. PMID: 20022087

The purpose of this Chinese study was to evaluate the efficacy of intravesical instillation of hyaluronic acid (HA) after hydrodistention for the treatment of IC patients with a small bladder capacity. Bladder hydrodistention was carried out in 47 patients with IC (aged 27-76 years) with a functional bladder capacity less than 200 ml. 20 patients then received intravesical instillation of 40 mg HA weekly in the first month and then monthly in the following 2 months. 16 patients received intravesical heparin instead of HA and 11 patients received hydrodistention alone as a control group. 3 months after hydrodistention, there was no improvement in the control group. 6 and 9 months after hydrodistention, improvement was significantly higher in the HA group than in the heparin group. At 9 months, heparin treatment did not show any improvement while improvement was still significant in the HA group. It was concluded that intravesical HA may prolong the effect of bladder hydrodistention in patients with severe IC. The effect of HA was shown to be better than that of heparin.

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, and Urologic Pelvic Pain Collaborative Research Network. Urology. 2009 Nov;74(5):983-7, quiz 987.e1-3. Epub 2009 Oct 2.PMID: 19800663

A single instrument – the Genitourinary Pain Index or GUPI – has been developed to assess the patient's reponse to treatment in clinical trials and studies involving both men and women. The GUPI was developed by modifying and adding new questions to the existing National Institutes of Health-Chronic Prostatitis Index. In this study the GUPI was shown to discriminate between men with chronic prostatitis (CP) or interstitial cystitis (IC), those with other symptomatic conditions, and those with none of these diagnoses. It also discriminated between women with IC, those with in continence,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.

PAINFUL MYOFASCIAL TRIGGER POINTS AND PAIN SITES IN MEN WITH CHRONIC PROSTATITIS/CHRONIC PELVIC PAIN SYNDROME.

Anderson RU, Sawyer T, Wise D, Morey A, Nathanson BH. J Urol. 2009 Dec;182(6):2753-8. Epub 2009 Oct 17. PMID: 19837420

Although a combination of manual physiotherapy and specific relaxation training is effective in treating men with CP/CPPS, there is little information on myofascial trigger points and specific chronic pelvic pain symptoms. This study reports on relationships between trigger points and pain symptoms in men with CP/CPPS in a group of 72 men. The authors found that certain myofascial trigger points at specific sites reproduce pain sensations in a substantial number of men with chronic pelvic pain. The authors are of the opinion that identifying the site of trigger point clusters both inside and outside the pelvic floor may help us to understand the role played by muscles in this disorder and provide insight into focused therapy.

In an editorial comment J. Krieger notes that the "conclusions of this study require confirmation by other groups and most importantly proof that identifying specific trigger points provides clinically meaningful information that should direct therapy."

URODYNAMIC TESTING AND INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME

D.N. Sastry, K.M. Hunter and K.E. Whitmore. Int Urogynecol J Pelvic Floor Dysfunct. 2009 Oct 16 [Epub ahead of print]. PMID: 19834634

In this retrospective chart study of 115 patients, the purpose of Sastry and colleagues was to evaluate the relationship between the severity of IC/PBS symptoms, urodynamic testing (UDT) and cystoscopy. Current diagnosis relies on history, physical examination and exclusion of confusable disorders. There is little literature on the role of urodynamics in IC/PBS and - as the authors point out - studies have been inconclusive so far in finding a role for UDT in diagnosing IC/PBS. The authors conclude that this study showed a significant association between symptom severity in IC/PBS patients and certain cystometric parameters and that assessment of pain, pressure or discomfort with bladder filling may be a key in urodynamic testing in IC/PBS patients. Additionally they are of the opinion that UDT objectively shows pain to be present and confirms symptom severity. This retrospective study had a number of limitations and prospective studies are needed.

TWO-YEAR EFFICACY AND SAFETY OF BOTULINUM A TOXIN INTRAVESICAL INJECTIONS IN PATIENTS AFFECTED BY REFRACTORY PAINFUL BLADDER SYNDROME.

Giannantoni A, Mearini E, Del Zingaro M, Proietti S, Porena M. Curr Drug Deliv. 2009 Oct 29. [Epub ahead of print]. PMID: 19863481

In this study from Italy, Giannantoni and colleagues report the 2-year efficacy and tolerability of intravesical botulinum A toxin (BoNT/A) injections in 13 female patients with painful bladder syndrome (PBS) with increased urinary frequency who have failed to respond to conventional treatments. The patients underwent preliminary evaluation using e.g. a voiding diary, urodynamics, urinary tract ultrasound and pain assessment. All patients were given multiple injections of 200 U BoNT/A diluted in 20 ml 0.9% NaCl, under cystoscopy. At 1 and 4 months, ten patients reported a subjective improvement. Average pain scores and daytime and night-time frequency decreased significantly. The authors note that 9 patients at 1 month and 7 at the 4-month check-up complained of dysuria. The three patients who failed to respond to the first session of intravesical treatment underwent another session three months later with satisfactory results. At 1 and 2 years follow up the beneficial effects persisted in all patients. No systemic side effects were observed during the study period. The authors conclude that intravesically injected BoNT/A is effective and safe in the medium-term management of patients with PBS. Repeat injections were required as the beneficial effect decreased within a few months after treatment.

CYSTODISTENSION: CERTAINLY NO STANDARDS AND POSSIBLY NO BENEFITS-SURVEY OF UK PRACTICE.

Mahendru AA, Al-Taher H. Int Urogynecol J Pelvic Floor Dysfunct. 2009 Nov 10. [Epub ahead of print]. PMID: 19902133

The authors claim that cystodistension is not a standardised procedure, although being used for various indications including interstitial cystitis. In this survey, 486 questionnaires were posted to consultant gynaecologists, urologists and urogynaecologists in the UK to evaluate current practice concerning indications,

technique, benefits and complications of cystodistension. 39% responded. The most common indication for use of cystodistension was interstitial cystitis. The authors conclude that cystodistension has a role in clinical practice, but its indications and benefits are still controversial and there is a wide variation in the technique used due to lack of standardisation.

Comment: In 2004, the European Society for the Study of IC/PBS (ESSIC) published the first of several articles aimed at standardizing diagnostic investigations for IC/PBS, including cystoscopy and hydrodistension, not mentioned in this UK paper.

LONG-TERM OUTCOMES OF URGENCY-FREQUENCY SYNDROME DUE TO PAINFUL BLADDER SYNDROME TREATED WITH SACRAL NEUROMODULATION AND ANALYSIS OF FAILURES.

Powell CR, Kreder KJ. J Urol. 2010 Jan;183(1):173-6. PMID: 19913835

Powell and colleagues present their long-term experience (January 2000 to July 2004) with sacral neuromodulation devices placed in patients (32 women, 7 men) with IC/PBS who had failed to respond to conventional treatment in order to determine whether the benefit decreases over time. Before 2003 a percutaneous test lead was placed in the clinic, while after 2003 a quadripolar permanent lead was placed in the operating room. 22 of the 39 patients went from test stimulation to permanent implantation (based on 50% symptom relief). The authors note that there were significant differences in short-term but not long-term outcomes between the 2 methods of test stimulation. They conclude that IC/PBS patients appear to respond best to permanent quadripolar lead placement but that long-term results do not appear to be independently affected by the method of test stimulation.

INTRAVESICAL LIGNOCAINE IN THE DIAGNOSIS OF BLADDER PAIN SYNDROME.

Taneja R. Int Urogynecol J Pelvic Floor Dysfunct. 2009 Nov 21. [Epub ahead of print]. PMID: 19936591

The purpose of this study with 22 women was to differentiate between pain originating from the bladder and pain coming from other pelvic organs, using intravesical instillations of 20 ml of 2% lignocaine solution and assessment of improvement based on a more than 50% drop in visual analogue scale pain score. 15 of the women experienced a significant reduction in pain. Of the 7 who failed to respond, 2 proved to have endometriosis, 4 were diagnosed as pelvic inflammatory disease and 1 had diverticulitis. Taneja concluded that intravesical lignocaine appears to be useful in excluding patients with pelvic pain originating from organs other than the urinary bladder.

PELVIC PAIN AND SURGERIES IN WOMEN BEFORE INTERSTITIAL CYSTITIS / PAINFUL BLADDER SYNDROME.

Langenberg PW, Wallach EE, Clauw DJ, Howard FM, Diggs CM, Wesselmann U, Greenberg P, Warren JW. Am J Obstet Gynecol. 2009 Dec 18. [Epub ahead of print]. PMID: 20022588

The purpose of the study was to compare IC/PBS patients with matched controls with regard to prior surgeries and possible surgical indications they had undergone.

Although women with IC/PBS were more likely to have experienced prior surgery than controls, the apparent reasons for the surgery, not the surgery itself, were stronger risk factors for IC/PBS. In particular, a prior history of chronic pelvic pain (CPP) appeared to have a strong association with IC/PBS. Several study design features, including extensive medical record review, suggest that prior CPP was not

undiagnosed IC/PBS. Further investigation into CPP may produce insight into the pathogenesis of IC/PBS.

BLADDER PAIN SYNDROME INTERNATIONAL CONSULTATION ON INCONTINENCE.

Hanno P, Lin A, Nordling J, Nyberg L, van Ophoven A, Ueda T, Wein A. Neurourol Urodyn. 2010;29(1):191-8. PMID: 20025029

The task assigned to the Painful Bladder Syndrome/Bladder Pain Syndrome Committee of the International Consultation on Incontinence (ICI) was to review developments in the field in the previous 4 years regarding definition, nomenclature, taxonomy, epidemiology, etiology, pathology, diagnosis, symptom scales, outcome assessment, principles of management, specific therapies and future directions in research. Since there was (and still is) no international consensus on nomenclature, the ICI Scientific Committee itself (described in the article as the “Consultation”) took the decision to recommend a change of name to BPS at the ICI Meeting in 2009, based on pain taxonomy of the International Association for the Study of Pain. A definition proposed by the PBS/BPS Committee is pain, pressure, or discomfort perceived to be related to the bladder with at least one urinary symptom, such as frequency not obviously related to high fluid intake, or a persistent urge to void. The Committee recommended that initial assessment should consist of a frequency/ volume chart, focused physical examination, urinalysis, and urine culture. Urine cytology and cystoscopy are recommended if clinically indicated. Treatment begins with conservative management, then variety of oral and intravesical therapies, with most surgical treatment reserved for severe patients who fail to respond to other treatment. It is noted that pain management is critical throughout the treatment process. The PBS/BPS Committee also suggests future research pathways.

OVERACTIVE BLADDER: A NEW PARADIGM

Blaivas JG. Int Urogynecol J Pelvic Floor Dysfunct. 2009 Oct 29. [Epub ahead of print]. PMID 19865783

An editorial with a sceptical look at terminology and a new proposal for defining overactive bladder and urgency. Very amusingly written, but oh so true! This editorial will be enjoyed by all those interested in standardization of terminology.

ABSTRACT

12th ANNUAL EUROPEAN CONGRESS INTERNATIONAL SOCIETY FOR PHARMACOECONOMICS AND OUTCOMES RESEARCH (ISPOR)
24-27 October 2009, Paris, France
RESEARCH ABSTRACT, SECTION: URINARY/KIDNEY DISORDERS – PATIENT-REPORTED OUTCOMES STUDIES, published in Value in Health, Vol 12. Number 7.2009

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HOW DO PATIENTS DESCRIBE THEIR SYMPTOMS OF INTERSTITIAL CYSTITIS/PAINFUL BLADDER SYNDROME (IC/PBS)? QUALITATIVE INTERVIEWS WITH PATIENTS TO SUPPORT THE DEVELOPMENT OF A PATIENT-REPORTED SYMPTOM-BASED SCREENER FOR IC/PBS

Abraham L, Arbuckle R, Bonner N, Crook T, Humphrey L, Mills IW, Moldwin RM, Nordling J, Scholfield D, Symonds T, van de Merwe JP.

In this study by Pfizer, the purpose was to conduct interviews with patients to identify key IC symptoms, and the language used to describe them, and to develop a new symptom-based IC screener. 44 IC/PBS patients with a confirmed diagnosis in the US, France and Germany (aged 22–72) were interviewed about their symptoms and

subsequent impact on quality of life. 10 United States overactive bladder (OAB) patients (aged 31–69) were also interviewed to improve specificity. Interviews included open-ended questions, creative tasks and focused discussion. Key symptoms identified by IC/PBS patients were the urge to urinate, urination frequency, and pain. Urge had four components: 1) need to urinate driven by pain; 2) a need to urinate to avoid pain getting worse; 3) a constant need to urinate and; 4) a sudden need to urinate. In contrast, OAB patients reported urge that did not involve pain. Both OAB and IC/PBS patients experienced high day and night-time urination frequency. IC pain was perceived to be in the bladder, abdomen or pelvis, and was most commonly described as "pressure", "burning", "sharp" and "discomfort". These data were used to develop items in the new screener. The authors emphasize that it is critical to optimize the sensitivity and specificity of the new screener in order to accurately identify patients with IC/PBS.

OVERVIEW UPCOMING EVENTS
2010

P.U.R.E. H.O.P.E. (Pelvic & Urological Resources & Education)
2010 Annual Pelvic Health Patient Education Day Conference, 20 February, 2010, 7:30 a.m. to 4:30 p.m. (Registration 7:30 – 8:30 a.m.) at Crowne Plaza GreensPoint, Houston, Texas, USA. **Meet the Speakers Reception**: Friday, 19 February, 2010, 4:30 p.m. – 6:30 p.m.
IAPO 4th Global Patients Congress, 23-25 February 2010 Istanbul, Turkey.
VIth International Conference On Rare Diseases And Orphan Drugs (ICORD 2010) "Global Accessibility And Neglected Diseases", 18-20 March 2010, Academia Nacional de Medicina, Buenos Aires, Argentina.
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 Conference 2010, 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.
PUGO Satellite Symposium: CURRENT CONCEPTS OF UROGENITAL PAIN
29 August 2010.

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

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 during the year 2009.

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