

International Painful Bladder Foundation

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

IPBF E-Newsletter, Issue 9, September 2007

Dear PBS/IC patient support groups, country contacts, healthcare professionals and friends around the world,

We once again have pleasure in sending you an update on international developments in the field of interstitial cystitis and painful bladder syndrome.

International Continence Society (ICS) annual conference, 20-24 August 2007, Rotterdam

The ICS kindly gave the International Painful Bladder Foundation a complimentary booth which received an unprecedented number of visitors throughout the ICS 2007 conference. IPBF board member Florentina Ferreyra, president of the Mexican support group, was in Rotterdam to help with the booth, assisted by two other members of the Mexican patient support group: Rocio Malja and Dorotea Prieto. Many thanks to them for their hard work and enthusiasm.

It was particularly evident at ICS 2007 that there is a rapidly increasing interest in PBS/IC by physiotherapists who are now playing a much greater role in treatment.

Many of the doctors participating in this conference told us that they would like some kind of patient support group because they have seen that the patients can help each other with advice and emotional support. But it is not easy to get a support group going with this group of patients. Patients are often reluctant to take on commitments. We have guidelines on our IPBF website, but these need to be adapted to the specific country and culture. The IPBF is always willing to give help and guidance in this respect.

While awareness of PBS/IC is increasing around the world, in many countries it is still limited to a small number of doctors. Treatment remains a problem, particularly for the patients with a more severe form of PBS/IC. Many of the specialists have limited treatment possibilities at their disposal in their country for these patients. Diagnosis is still a difficult hurdle with the primary care level being the main stumbling block. Every effort has to be made to increase awareness at a primary care level.

A review of all workshops, presentations and posters related to PBS/IC at ICS 2007 may be found on the IPBF website:

http://www.painful-bladder.org/pdf/2007_ICS_Rotterdam.pdf

An innovation at this year's ICS conference was a session on Lifestyle with a focus on the patient and quality of life. A study into whether Diet Coke causes overactive bladder symptoms in normal volunteers found that daytime frequency appears to be significantly increased by drinking Diet coke or caffeine free Diet Coke, whereas frequency was unchanged with Classic Coke. They concluded that artificially sweetened drinks appear to cause increased urinary frequency, mean urinary urgency and urgency episodes. A similar conclusion was reached in the case of PBS/IC patients and artificial sweeteners in the article on the Effect of comestibles on symptoms of interstitial cystitis by B. Shorter, M. Lesser, R.M. Moldwin and L. Kushner in the Journal of Urology, July 2007.

Another presentation in this session led to a question as to how much people should actually drink each day in order to remain healthy. This stimulated a lively discussion into the problems caused by the current vogue for drinking huge quantities of mineral water as recommended by health magazines and websites in order to keep fit and to aid in dieting. Everywhere you go these days, you see people sipping from bottles of water, according to Professor Linda Cardozo. This fad has not surprisingly caused urologists' waiting rooms to be filled with people suffering from the consequences including excessive urinary frequency and possibly night-time frequency which clear up once they stop over-drinking. However, it is also apparent that people suffering from overactive bladder or urinary incontinence are more likely to suffer more severe symptoms if they drink an excessive fluid load, while some PBS/IC patients on the other hand may experience more painful urination if they drink too little and their urine becomes very concentrated. An amount of 24 mls fluid intake per kilo body weight per day was recommended for a healthy lifestyle in a temperate climate. This will average at around 1500 ml fluid intake per day (including all fluid intake such as soups, coffees, teas, water etc) for an average-sized person. Obviously fluid intake would need to be increased in a hotter climate and/or in the case of excessive perspiration, heavy exercise etc.

It was also emphasised in this Lifestyle session that it is essential for patients to understand their anatomy and how their body works and that there is clearly a need for more patient education to ensure that patients can understand what their treatment is supposed to achieve, how and why.

Societe Internationale d'Urologie (SIU), Annual Conference, 2-6 September, Paris

Only one week after the ICS conference, the IPBF was setting up its complimentary booth in Paris at the SIU conference for the very first time. This time we shared the booth with Françoise Watel, president of the French IC support group AFCI. Here at SIU we made many new contacts from developing countries, including Africa where we had few contacts until now. And it was always the same story of unaffordable and/or unobtainable drugs with many doctors not fully aware of the cheaper generic drugs that can be used for PBS/IC, including in cocktails. However, even cheap intravesical treatment is not always the answer when you have insufficient supplies of disposable catheters. Infection then becomes a very real risk. We must not forget these countries and the very different and often difficult conditions under which healthcare is practised and patients have to live.

A frequently heard comment from doctors at this conference was that they would like to see some kind of sub-grouping of IC patients, perhaps according to symptoms, but in some way that would make treatment selection easier. The current trial & error basis of most treatment for IC is proving very costly. Many patients and hospitals in developing countries simply cannot afford this.

European Commission Rare Diseases Research conference – 13 September, Brussels

The IPBF was represented at this research conference by its chairman who was kindly sponsored by the European Commission. The aim of this top EU conference attended by government authorities, research institutes, industry, doctors and patients was:

- to promote Rare Diseases as a priority of the European Union's political research agenda.
- to increase the visibility of Rare Diseases research
- to raise awareness at the level of Member States and European Parliament of research needs in this field

- to provide the Rare Diseases community with the opportunity to express their needs in terms of research in the context of the 7th Research Framework Programme (FP7), strengthening at the same time dialogue between stakeholders and the European Commission.

In the European Union a disease is considered rare when it affects less than one person in 2,000 (In the USA a disorder is considered rare when it affects fewer than 200,000 people in the whole country). It is estimated that there are some 6,000 to 7,000 different rare diseases. When you add this up, it totals around 34 million people across Europe suffering from a rare disease, according to Janez Potočnik, European Commissioner for Science & Research in a videoed message. He stated that the causes of these diseases are poorly understood, patients may be misdiagnosed and so given inappropriate treatment, and even once the correct diagnosis is made there is not always a therapy or treatment available. It is therefore essential to work across borders to ensure larger patient numbers for trials, while specialists throughout Europe can cooperate in the field of diagnostics and treatment. For patients there is the added value of being able to communicate with fellow-sufferers from other countries and exchange experiences. It was emphasised that patient organisations for rare diseases can potentially play an important role in research programmes.

It was also underlined that rare diseases can serve as models for more common diseases while tools, methods and products developed from research into rare diseases can often be applied in more common diseases, thereby benefiting an even wider public.

Further information about rare diseases in the EU:

http://ec.europa.eu/health-eu/health_problems/rare_diseases/index_en.htm

Information about participation in FP7:

http://cordis.europa.eu/fp7/participate_en.html

Rare disease patient groups in the European Union, information on the Eurordis website:

http://eurordis.org/article.php3?id_article=1531

Useful sources of information on PBS/IC

In addition to the many patient-driven websites, many of which contain extensive information for both patients and professionals, including of course our own site www.painful-bladder.org, there are now a number of other websites that are a useful and valuable source of information for patients and/or professionals, including the following:

Smith Institute for Urology

The Smith Institute for Urology in New York, where Dr Robert Moldwin is now director of the Urological Pelvic Pain Center, has a useful site for patient-friendly information on IC:

http://www.smithinstituteforurology.com/patient_pelvic_cystitis.html

University of Maryland

The University of Maryland Interstitial Cystitis Center: <http://icresearch.umaryland.edu/> has details of the Maryland Genetics of Interstitial Cystitis (MaGIC) and Events Preceding Interstitial Cystitis (EPIC) studies, a section detailing its recent scientific publications including posters on: <http://icresearch.umaryland.edu/publications.asp> and its IC newsletter on current IC research at the University of Maryland:

<http://icresearch.umaryland.edu/documents/Newsletter%20Issue%205%20Spring%202007.pdf>.

This centre has been asking patients in the EPIC study what sensations they experience when they have an urge to void, which is a further, very gratifying development at a scientific level of the patient survey done by us a year ago and presented as a poster at the NIDDK symposium.

ESSIC website

The website of the European Society for the Study of IC/PBS www.essic.eu also contains useful information and literature references.

IC in Romania

For Romanian-speakers, there is a new patient website on bladder disorders: www.cistita.ro with a section on interstitial cystitis: <http://www.cistita.ro/boli/cistita-interstitiala.php>. In addition to IC, this site also covers neurogenic and overactive bladder. One of the initiators of this project is neurourologist Dr Andrei Manu-Marin who is working hard to raise awareness of IC in his country. He explained that they decided to start with patient information because it is the most direct way of helping people and a website is the cheapest way of achieving this objective. This kind of project is particularly valuable in non-English speaking countries where there is as yet no patient support group.

Pelvic Floor Website

A pelvic floor website by consultant physiotherapist Professor Grace Dorey is: www.yourpelvicfloor.co.uk with information on pelvic floor exercises for men and women, including self-help books for patients which can be ordered online, as well as information for professionals and useful press releases on different topics.

Revised IPBF brochure

The IPBF brochure on PBS/IC: Diagnosis & Treatment has once again been updated and can be found at: http://www.painful-bladder.org/pdf/Diagnosis&Treatment_IPBF.pdf

It includes a revised and enlarged list of questions to assess the possibility of a PBS/IC patient having associated disorders as a useful first screening for the presence of these disorders, kindly contributed by Joop van de Merwe, MD. This list is also available separately at:

<http://www.painful-bladder.org/pdf/QuestionsAssDisPBS.pdf>

NIDDK taking a multidisciplinary approach to a research definition of the urologic chronic pelvic pain syndromes

On December 13th and 14th a draft of new research definitions/diagnostic protocols of the Urologic Chronic Pelvic Pain Syndromes – most commonly IC/PBS and chronic prostatitis - defined in relation to their co-morbid disorders, and developed using existing published literature, will be drawn up by an international panel of clinician experts. These clinicians will then “field-test” the definitions/protocols at their clinics. There will be an opportunity to comment by Email on the proposed definitions, prior to the December meeting. All of these Email comments will be presented to the expert panel.

A symposium will then be held in 2008 to evaluate the field testing results and to adjust the draft definition/diagnostic protocol to the pertinent findings of these studies. At this meeting, an open forum will also be held for comments from all interested parties. The definitions developed at the 2008 meeting will then be published and used for future NIDDK funded clinical studies. It is realized that the definitions finalized in 2008 will be based on the current published literature which leaves many relevant questions unanswered. As more peer-reviewed data is published, the definitions will be reviewed and adjusted, if necessary, to ensure the definitions reflect the most recent published data.

For further information please contact Ms. Cerena Cantrell, The Scientific Consulting Group, Email: ccantrell@scgcorp.com.

Information on the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network and the RFA Fact Sheet for researchers can be found at:

http://www.painful-bladder.org/2007_NIH_MAPP.html

IPBF Questionnaire Survey study - reminder

The IPBF is currently conducting a questionnaire survey study for urologists and (uro)gynaecologists diagnosing and treating PBS/IC patients in the community around the world. The aim of this survey is to obtain a clearer picture about the specific situation relating to diagnosis, treatment and other aspects of PBS/IC in specific countries. The questionnaire is available on the IPBF website home page (www.painful-bladder.org) in MS Word and can be downloaded and filled in, either on your computer or by hand and then either emailed, faxed or posted to us. The deadline is the end of December 2007. The IPBF would be very grateful for your cooperation.

We would like to thank all the doctors who so kindly took the time to fill in the questionnaire at the ICS and SIU conferences.

New Scientific Literature on IPBF website

A continually updated selection of new scientific literature can be found on our website: <http://www.painful-bladder.org/pubmed.html>.

New scientific articles of interest include:

Interstitial cystitis and systemic autoimmune diseases

Van de Merwe JP. Nat Clin Pract Urol Sep;4(9):484-91.
PMID: 17823601

Review article. Autoantibodies have been found in patients with IC, but are likely to be secondary to the disease. While no data support a direct causal role of autoimmune reactivity in the pathogenesis of IC, indirect evidence does support a possible autoimmune nature of IC, such as high female preponderance and clinical association between IC and other known autoimmune diseases. The strongest association occurs between IC and Sjögren's syndrome. Autoantibodies to the M3 receptor might be important in both the early non-inflammatory and late inflammatory features of IC.

The role of the bladder surface in interstitial cystitis/painful bladder syndrome.

Teichman JM, Moldwin R. Can J Urol. 2007 Aug;14(4):3599-3607.
PMID: 17784979

Numerous factors have been implicated in the pathogenesis of IC. A literature review was conducted on the following topics: urothelium, mucosal lining, interstitial cystitis, bladder, and glycosaminoglycans. A commonly proposed cause for IC is a defect or alteration in the bladder surface. This concept is supported by studies of the structure, function and composition of the bladder surface. The cause(s) is not yet known although research has indicated that levels of growth factors and/or compounds protecting the bladder wall could be implicated. Alterations in the bladder surface are observed in IC and may play an important role in its etiology.

Dilemmas in diagnosing pelvic pain: multiple pelvic surgeries common in women with interstitial cystitis.

Ingber MS, Peters KM, Killinger KA, Carrico DJ, Ibrahim IA, Diokno AC.
Int Urogynaecol J Pelvic Floor Dysfunct. 2007 Sept 18; [Epub ahead of print].
PMID: 17876490

In this study it was found that women with IC had a statistically higher prevalence of hysterectomies, bladder suspensions, pelvic or genital surgeries and laparoscopic pelvic surgeries. The diagnosis of IC occurred 1-5 years after hysterectomy in most cases. Women with IC have significantly more pelvic surgeries than controls. The majority of these were done before diagnosis of IC and may be performed for pain related to undiagnosed IC.

Resiniferatoxin and botulinum toxin type A for treatment of lower urinary tract symptoms.

Cruz F, Dinis P. *Neurourol Urodyn*. 2007 Aug 17; [Epub ahead of print].

PMID: 17705161

Resiniferatoxin (RTX) and botulinum toxin A (BTX-A) are increasingly viewed as potential treatments for refractory LUTS. Recent data suggest a role for these neurotoxins in treating urgency in OAB, while experimental data support their use in treating pain and frequency in IC/PBS, although results from trials for the latter are still inconclusive. Despite promising results, administration of these neurotoxins is still experimental and more clinical studies are necessary before a license for their use will be issued by health authorities.

Overlap of voiding symptoms, storage symptoms and pain in men and women.

Clemens JQ, Markossian TW, Meenan RT, O'Keefe Rosetti MC, Calhoun EA.

J Urol. 2007 Oct;178(4):1354-8. Epub 2007 Aug 16.

PMID: 17706719

This study found that pain symptoms commonly coincide with voiding and storage problems in men and women. This suggests that categorizing patients into disease categories, such as LUTS or bladder conditions, may ignore the pain components of symptoms. A symptom-based classification system may more accurately identify and address all patient complaints.

Book review:

Penn Clinical Manual of Urology. Edited by Philip M. Hanno, Alan J. Wein, S. Bruce Malkowicz. Published by Saunders, Elsevier. ISBN-13: 978-1-4160-3848-1.

This easy-to-read, compact manual of urology contains a chapter (chapter 7 pp 217-234) on Painful Bladder Syndrome (Interstitial Cystitis) by Philip M. Hanno, MD. It provides a clear, uncomplicated overview of this complicated topic. Although written for clinicians, many patients would also find this chapter a useful reference resource.

Upcoming events:

5-6 October 2007: IACM 4th Conference on Cannabinoids in Medicine, Cologne, Germany

27-28 November 2007: 4th European Conference on Rare Diseases, Lisbon, Portugal.

20-22 February 2008: 3rd IAPO Global Patients Congress, Budapest, Hungary

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!

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

We would like to take this opportunity of thanking our sponsors the Medtronic Foundation, Medtronic Trading Sarl and Bioniche Pharma Group Ltd for their greatly appreciated financial support for our foundation, projects, website and newsletters.

With best wishes

Jane Meijlink

Chairman IPBF

On behalf of the Board of the

International Painful Bladder Foundation

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www.painful-bladder.org

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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