

International Painful Bladder Foundation

*The **IPBF** is a voluntary non-profit organisation*
www.painful-bladder.org

IPBF Newsletter – January 2006

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

New Foundation

On 1 January 2006, the new INTERNATIONAL PAINFUL BLADDER FOUNDATION officially replaced the former IICPN Foundation. Activities of the old foundation will henceforth continue under the new name.

Links

If you had a link on your own website to the old IICPN Foundation, would you please change this to the new International Painful Bladder Foundation, www.painful-bladder.org

New website

We have a new website: www.painful-bladder.org with a new approach. Although the focus of the foundation remains on painful bladder syndrome/interstitial cystitis, we are endeavouring to place it in a wider context. If you glance down the website menu, you will see that in addition to detailed information on PBS/IC, we have provided overviews of other painful bladder disorders (infectious, non-infectious and a section on prostate disorders), overactive bladder syndrome and urinary incontinence. This allows visitors to the site to compare symptoms and see where there may be overlapping conditions. For example, some PBS/IC patients may also have an overactive detrusor or they may also have stress incontinence or men may have IC and prostatitis. There are many possible permutations.

If you click on PBS/IC and associated disorders on the menu, you will find an overview of many conditions that can occur in association with PBS/IC, varying from allergy to Sjögren's syndrome. This section also includes a number of in-depth articles on specific conditions.

Awareness of all these overlapping conditions and combinations will hopefully help to ensure more effective all-round treatment and a better understanding of PBS/IC in a wider setting.

Up-to-date information

Virtually all information on the site has been updated, rewritten or newly written. Setting up a new website is an ideal opportunity for a thorough spring-clean!

The new IPBF site provides information for patients and professionals, a continually updated selection of new scientific literature on PBS/IC and relevant topics and much more besides.

Site map

We now have a site map (index) on our website which makes it easier for visitors to the website to find what they are looking for. Click on a word and it will take you to the text on that subject.

Terminology on the IPBF website and publications

Since some people are using the term painful bladder syndrome, others interstitial cystitis and there is still no worldwide consensus as to where the one ends and the other begins, we have chosen to use the term PBS/IC on the website in order to avoid confusion, except in an

historic context or a context where research or studies have been carried out with patients specifically diagnosed as IC patients.

Suggestions from you

We are open to suggestions: if you think that there is something we should include on the website or in our publications, please let us know. We greatly value your input.

New toilet cards

The old IC toilet card in English for quick access to public toilets has been rewritten and we now also have a toilet card for patients with overactive bladder. These can be found on the website menu under IPBF Publications or go direct to:

PBS/IC: <http://www.painful-bladder.org/pdf/tcenglish.pdf>

OAB: http://www.painful-bladder.org/pdf/tcenglish_OAB.pdf

IPBF booth at EAU congress

The IPBF will be organising an information booth – the first under the new name - at the annual congress of the European Association of Urology, 5-8 April 2006 in Paris. Our booth will be B18. We look forward to seeing you.

Located right next to us at B17 will be the French patient support group: Association Française de la Cystite Interstitielle, thereby providing a total of 6 metres of booth information on PBS/IC and associated disorders! With the congress being held in Paris this year, it will be a perfect opportunity for French doctors (and doctors from other French-speaking countries) to make contact with this active French support group.

EAU congress course on CPPS and PBS/IC

The EAU Congress in Paris will include a course (ESU course 8, 6th April) on Chronic pelvic pain syndrome (CPPS) with special focus on chronic prostatitis (CP) and painful bladder syndrome/interstitial cystitis, chaired by Prof. J. Nordling.

Polish PBS/OAB seminar

At the beginning of December 2005, the IPBF did a “pilot launch” of the new foundation in Warsaw, with an informal info table at the 4th Warsaw Seminar on Neurourology, organised by Professor Andrzej Borkowski and Dr Piotr Radziszewski of Warsaw University and attended by some 370 Polish urologists, gynaecologists and neurologists. The title of the seminar was “Nocturia, overactivity and pain – symptoms or syndrome?” A report on this successful seminar can be found on our website: http://www.painful-bladder.org/2005_Warsaw.html. A very clear update on the diagnosis and treatment of PBS/IC was given by Professor J-J Wyndaele.

The IPBF info table in Warsaw, with material on PBS/IC and our new OAB brochure, was a great success, so much so that our table was completely empty after two hours and we had to take email addresses to email the information to disappointed customers! This underlines the value of providing this kind of background information at national meetings and specialised symposia as well as international congresses.

Selected new scientific literature

A selection of new scientific literature on PBS/IC and relevant related topics, with links to PubMed abstracts where available, can be found on our site at:

<http://www.painful-bladder.org/pubmed.html>

There is a link in this section of our site to the complete abstract book of the [Scientific Workshop on Chronic Pelvic Pain/Chronic Prostatitis](#) held in October 2005 and sponsored by the NIDDK. These abstracts provide very interesting new insights into the entire field of chronic pelvic pain.

The review paper, listed in the literature section, by Prof. J.J. Wyndaele on "Evaluation of patients with Painful Bladder Syndrome/Interstitial Cystitis" is a source of useful and practical information for everyone involved in PBS/IC.

PBS/IC in Czech Republic

Congratulations to Drs Zámečník, Hanuš, Pavlík, Dundr and Povýšil on their article on INTERSTITIAL CYSTITIS - DIAGNOSIS AND TREATMENT in Czech in the Czech medical journal Časopis Lékařů Českých, Supplement 2/2005, 30. Výročí Založení Urologické Kliniky 1. LF UK A VFN. (Čas. Lék. Čes., 2005, 144 (Suppl.2), pp 2S23-2S29). This was a perfect opportunity to greatly increase awareness and understanding of PBS/IC among a wide readership of doctors from all disciplines throughout the Czech Republic.

Webcasts – chronic pelvic pain

Conference webcasts are becoming increasingly popular and are ideal for those with neither the time nor the means to travel round the world.

On the EAU website www.uroweb.org, under *Tenerife webcasts*, there is a presentation on Chronic Pelvic Pain by Prof. T. Hanuš from Prague. So when you have a spare moment, enjoy this presentation from the comfort of your own armchair!

Patient Survey on the Definition of PBS/IC

Many thanks to all those from many different countries who responded to this survey. The very interesting responses are currently being analysed and it is hoped to publish the results later this year.

Patient support group news

PBS/IC reminder card for family doctors

The Cystitis & Overactive Bladder Foundation in the United Kingdom has produced a simple but ingenious 13 x 13 cms plastic-coated card for family doctors to remind them when to suspect painful bladder syndrome/interstitial cystitis in their patients. Further information from info@cobfoundation.org.

Belgian patient conference

The Belgian support group, Interstitiële Cystitis Patiëntenvereniging België (ICPB), is organising a patient conference (admission free) on Saturday 18 April 2006, at the Eurovolleybalcenter, Beneluxlaan 22, 1800 Vilvoorde, Belgium, starting at 14.00 hrs. The conference language will be Dutch. Further information from info@icpb.be.

Mexico on radio via internet

It was very exciting to be able to listen to Florentina Ferreyra, president of the Asociación de Enfermedades Uroginecológicas in Mexico (www.asenug.org), live on the radio via the internet. Florentina was interviewed for almost an hour on an Expresión Digital Radio programme on 20th January when she spoke on urogynaecological problems in women, PBS/IC, vulvodynia and urinary incontinence, about her own experiences, the difficulties of obtaining a diagnosis and how the Mexican support group was set up.

Calendar for the coming months

18 February 2006: Belgian patient conference, Vilvoorde, Belgium

22-24 February 2006: International Alliance of Patients' Organizations (IAPO). Global Patients Congress, Barcelona, Spain.

10 March 2006: Joint Meeting with the Section of Anaesthesia at the Royal Society of Medicine, Pain of Urogenital Origin (PUGO) and the British Society for the Study of Vulval Disease (BSSVD), London, United Kingdom.

5-8 April 2006: European Association of Urology (EAU) annual congress, Paris, France.

27-29 April 2006: 9th International Symposium on Sjögren's Syndrome, Washington DC, USA.

10-13 May 2006 World Meeting on Gynecological Pelvic Pain and Endometriosis, Milan, Italy.

20-25 May 2006: American Urological Association (AUA) annual conference, Atlanta, Georgia, USA.

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

Please note:

The NIDDK is planning an international scientific workshop and symposium on PBS/IC in October 2006. Further details and a definitive date will hopefully be available in the coming month.

Donations and sponsoring

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.

With best wishes

Jane Meijlink
Chairman IPBF
On behalf of the Executive Board

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