

International Interstitial Cystitis Patient Network Foundation

The IICPN Foundation is a voluntary non-profit organisation
www.iicpn-foundation.org

Newsletter - July 2005

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

Activities in the Painful Bladder Syndrome/Interstitial Cystitis world

The past few months have again been marked by considerable activity on the PBS/IC front: discussions, conferences, presentations and research. Experts and researchers around the world are constantly battling to find answers to this still frustratingly baffling painful bladder condition.

Much attention in the past year has been focused on terminology, definitions and criteria for interstitial cystitis. Different committees and organisations – including the ICI committee on PBS, ICS, NIDDK, ESSIC – have all been intensively debating these issues, but many problems still remain unsolved.

Still very inadequate awareness of PBS/IC worldwide

Despite all the developments and activities in the PBS/IC world, we should not be lulled into thinking that all countries are aware of PBS/IC and that all patients have access to information. On the contrary, there are still many countries where there is little or no awareness of this painful bladder condition and countries – even in Western Europe - where healthcare professionals claim that IC does not exist in their patient population. Consequently, many patients fail to receive the right diagnosis and are sent home in despair with no treatment or are even referred to a psychiatrist.

The PBS/IC world at all levels needs to address this situation by providing clear, up-to date information on diagnosis and treatment to both healthcare professionals and patients; furthermore by ensuring that there is consensus on the terminology and definitions used. Diagnostic procedures must be standardised, although the diagnostic procedures used by the general urologist will always depend on what is available and affordable in any given country.

In the past 2 years, although insights into diagnostic criteria among the experts have totally changed, this information is taking a very long time to filter down to the general urologist who may still be diagnosing IC on the basis of the old NIDDK criteria. Consequently we still hear from patients with pain, urgency and frequency symptoms who have been told that they cannot possibly have IC because e.g. their bladder capacity is too large.

Treatment is still a major problem around the world. Much of the treatment available in the USA and western countries is not available elsewhere or only at a prohibitively high price, with the result that in many countries only rich patients are able to receive this kind of treatment. In poorer countries, more attention should be paid to cheaper forms of treatment that are available and/or affordable in a specific country. When raising awareness of PBS/IC in these countries, special attention should therefore be paid to realistic treatment suggestions.

IC is a difficult enough disease for patients living in countries with good healthcare systems, homes with luxury bathrooms, pharmacies round the corner and doctors and facilities within easy reach. Just imagine what it is like for illiterate people living on the streets, in tents, in rural villages, in the bush, in the jungle, with no hygiene, little or no access to healthcare or education, no money for food let alone adequate treatment. The world of internet information, clean hospitals and healthcare for all is like a distant and unreachable star in the sky to these people who are only concerned with finding their next meal and a roof over their heads.

The question for the international IC world is how do we help raise awareness in these forgotten countries and how do you reach patients who are illiterate and therefore cannot even read a leaflet? One answer may be to work in cooperation with larger national or international organisations working on the ground, reaching out to local communities.

It is also a problem to raise awareness among healthcare professionals who speak little or no English. In countries where this is the case, it is mainly the university doctors who speak English and who are able to attend international conferences. This makes it particularly important for local national symposia to be organised in the language of the country itself.

Annual Conference of the American Urological Association, San Antonio 21-26 May 2005

It was very hot in San Antonio. And very cold inside the Henry B. Gonzalez Convention Center! And once again the IICPN Foundation booth was located right beneath a gale-force air-conditioning duct which blew the skirt of our table up like a parachute with the leaflets flying in all directions! However, this was quickly dealt with by very kind AUA staff who switched off the air-conditioning duct above our table. Florentina Ferreyra from Mexico and I were exceedingly grateful!

Info tables at conferences are still an important way of disseminating up-to-date information on the diagnosis and treatment of PBS/IC and associated disorders to booth-browsing doctors from many different countries around the world. We also provided them with simple patient leaflets in English that can be translated into their own language and culture.

As usual, there were many presentations and posters on PBS/IC at this AUA conference. Our report on the website (www.iicpn-foundation.org)

concentrates on the excellent course on PBS/IC given by IC-guru Philip Hanno MD and David Burks MD which updated delegates on the latest terminology, investigations, treatment and most recent insights.

Many thanks to Bioniche Life Sciences (www.bioniche.com) for funding the all-important printing costs for our IICPN Foundation booth at the AUA conference and thanks also to the AUA for the free booth space.

AUA Webcasts

Armchair delegates can find some interesting AUA presentations on the webcasts, including the Use of Botox in Urology, by surfing to www.aur2005.org/webcasts. The joy of webcasts is that if you miss a bit, or haven't understood it, you can simply replay it!

3rd ESSIC meeting Baden, Austria

The European Society for the Study of IC/PBS, chaired by Professor Jørgen Nordling, once again organised a very successful annual meeting 16-17 June in Baden, Austria, with scientific presentations and in-depth discussions on definitions and criteria for the diagnosis of PBS/IC. A review of the meeting by Professor Nordling is available on our website (www.iicpn-foundation.org) and further details will be published by ESSIC in due course.

Application forms for membership of ESSIC (doctors/researchers only) can be downloaded from the ESSIC website (under construction): www.essicoffice.org.

6th International Consultation on New Developments in Prostate Cancer and Prostate Disease, Paris 24-27 June included committee report on Prostatitis & Chronic Pelvic Pain

In recent years we have heard conflicting views on whether chronic non-bacterial prostatitis and chronic pelvic pain in men are the same as interstitial cystitis or not. This consultation was an ideal opportunity to hear the views of an international committee (committee 15) on Prostatitis & Chronic Pelvic Pain, chaired by Anthony Schaeffer MD. However, it seemed clear from this committee's report that even less is known about the causes of chronic non-bacterial prostatitis than about interstitial cystitis, despite the fact that the majority of men with prostatitis have the non-bacterial form! And treatment is equally a hit-and-miss affair. Sadly there was no discussion on the possible association with PBS/IC.

Tom Hudson MD, chairman of committee 16 on Patient's Perspectives in Prostate Disease and chairman of the European Prostate Cancer Coalition Europa Uomo, gave a most moving and insightful presentation on the patient perspective.

When asked about how to deal with the problem of getting information to illiterate patients, a panel member from the USA informed delegates that a substantial percentage of his patients with prostate cancer in the USA were also illiterate. This brought home to everyone the fact that illiteracy has by no means been eradicated in the west.

These two presentations will be available as webcasts in due course on www.smeonprostatehealth.com.

The committee reports will be published in book form next year.

Diet and PBS/IC: scientific studies needed

When exhibiting at congresses, we are frequently approached by healthcare professionals asking us about PBS/IC and diet. While there is as yet no scientific evidence that diet has an effect on PBS/IC, patients may indeed find in practice that certain foods and beverages seem to cause additional irritation of the bladder. This may fluctuate in some patients: the same foods and beverages may have a worse effect during a flare or period of exacerbation, but be better tolerated in a period of (relative) remission. Foods that commonly appear to cause irritation include: high acid food or beverages (particularly citric fruit or fruit juice, tomatoes, vitamin C tablets, etc), spicy food, chocolate and caffeinated beverages. It should be emphasised that this varies from patient to patient and it can be useful for individual patients to experiment with diet modification to see if it alleviates their symptoms. Scientific studies into diet and PBS/IC would perhaps shed some valuable light onto this aspect.

Portuguese leaflet

Thanks to Dr Paulo Dinis Oliveira, we now have a Portuguese translation of our IC leaflet. This is available on our website together with the Chinese, Dutch, French, Hebrew, Thai and Turkish versions.

Sjögren's Syndrome – English version

The English translation of the 12 page article on Sjögren's syndrome by Dr Joop P van de Merwe is now available on our website, together with the Dutch version. This provides a useful overview for healthcare professionals and for patients who have this autoimmune disease in association with PBS/IC and would like to know more about it.

NVA New Online Vulvodynia Teaching Programme

The National Vulvodynia Association (NVA) of the USA is pleased to announce the availability of the 2nd edition of its teaching programme for healthcare professionals. It is now available online free and includes a presentation on the differential diagnosis, treatment and aetiology of vulvodynia. Visit: <http://learn.nva.org>. There is also a link from the IICPN Foundation website.

The NVA is an excellent source of information for both patients and professionals on this difficult condition, sometimes found in association with PBS/IC.

Spanish translation of PUF questionnaire now available

A Spanish version of the Pelvic Pain and Urgency/Frequency (PUF) patient symptom scale has been translated and validated and is now available. See *Validation of Spanish version of Pelvic Pain and Urgency/Frequency (PUF) patient symptom scale*. S Minaglia, B Ozel, JN Nguyen, DR Mishell jr (*Urology*.2005 Apr;65(4):664-9.

NIDDK produces new updated booklet (IC/PBS)

The National Institute of Diabetes and Digestive and Kidney Diseases in the USA, better known to us all as the NIDDK, has produced a new patient booklet which it launched at the AUA conference this year. This booklet is written in very simple terms and can be found and downloaded at:

<http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/index.htm>. It is free for everyone to use.

ICS Standardisation reports

For anyone who would like to browse through ICS standardisation reports, they can be found on the ICS website www.icsoffice.org, select 'documents' in the menu, then in the ICS Documents Index click on Standardisation. The document on Lower Urinary Tract Function Standardisation can also be a very useful reference for patient organisations who may perhaps be uncertain of the meaning of certain terms or of the correct term to use.

Interesting uro-neuro article in European Urology Today

Although it may seem like slightly going off at the tangent in this context, the article in the EAU's EUT June 2005 on "A neurological approach to retention and obstructed voiding in women" by Soumendra N. Datta and Clare J. Fowler of the Department of Uro-Neurology, National Hospital for Neurology & Neurosurgery, London provides an interesting and clearly explained read on uro-neurology (or neuro-urology) and how it all works. Can be read at leisure on the website of the European Association of Urology (www.uroweb.org): go to Publications -> EUT -> EUT 2005 JUN. Or:

www.uroweb.nl/files/uploaded_files/EUT2005JUN.pdf

INCONTINENCE, edited by P. Abrams, L. Cardozo, S. Khoury, A. Wein – with chapter on Painful Bladder Syndrome

These 2 volumes (also available on CD Rom) contain the reports from the 25 international committees at the 3rd International Consultation on Incontinence in Monaco in 2004 where each chairman presented his or her committee's main discussions and recommendations. This book details the evidence reviewed by each committee. Chapter 23 (volume 2, pages 1455-1520) concerns Painful Bladder Syndrome (including Interstitial Cystitis) by the committee chairman Philip Hanno MD. It deals with the definition, aetiology, epidemiology, pathology, diagnosis, clinical symptom scales, assessing outcomes, conservative therapy, oral therapy, intravesical therapy, surgery and future directions. The chapter concludes with an assessment and treatment algorithm.

Well worth reading by anyone with an interest in PBS/IC and particularly valuable for professionals in the field of urology.

ISBN 0-9546956-2-3

The set of 2 books and/or CD Rom can be ordered from Les Editions 21, Email: editions21@wanadoo.fr.

New scientific literature

Selected new literature is listed on the IICPN Foundation website with links to PubMed abstracts where available. We have selected a couple of

interesting studies for this newsletter, more can be found on our website www.iicpn-foundation.org

Treatment of interstitial cystitis with Cystistat: a hyaluronic acid product. (Scand J Urol Nephrol.2005;39(2):143-7) EB Kallestrup, SS Jorgensen, J Nordling, T Hald.

A study from Denmark with intravesical hyaluronic acid concluded that hyaluronic acid safely reduced the pain and, to a lesser degree, the urinary frequency associated with IC.

Reinvestigation of patients with a diagnosis of interstitial cystitis: common things are sometimes common (J of Urology, vol 174,584-587, August 2005) by Paul Irwin & Azizan Samsudin

The importance of excluding all possible confusable diseases was underlined by Paul Irwin MD and Azizan Samsudin MD in this recent article on the reinvestigation of patients with a diagnosis of interstitial cystitis. As they state in their article: "It is difficult to say precisely what IC is. This study shows that it is considerably easier to say what it is not." Their study reinvestigated 61 patients previously diagnosed with IC and revealed that 27 (44%) did not in fact have IC. Their symptoms were shown to have other often very common causes. They conclude that "Precision in clinical diagnostics must be improved and while IC remains a diagnosis of exclusion it is incumbent on every urologist to ensure that common conditions are actively excluded."

The above article is particularly interesting when seen alongside a previous study last year in the USA: *A referral center's experience with transitional cell carcinoma misdiagnosed as interstitial cystitis (J.Urol. 2004 Aug;172(2):478-80) by WD Tissot, AC Diokno and KM Peters* in which the authors expressed some concern that the recent trend towards diagnosing IC in a non-invasive way could lead to other causes of the symptoms being missed, as demonstrated in their retrospective review of patient records.

A model of neural cross-talk and irritation in the pelvis: implications for the overlap of chronic pain disorders. (Gastroenterology. 2005 June; 128(7):1953-64) by MA Pezzone, R Liang & MO Fraser

This interesting article on the possible association of irritable bowel syndrome, interstitial cystitis and other chronic pelvic pain disorders concerns a study in which the authors investigated the hypothesis that afferent irritation of one pelvic organ may adversely influence and sensitize another via neural interactions. In other words cross-sensitization, or cross-talk, between organs which the authors believe may account for the substantial overlap of chronic pelvic pain disorders. Let's hope that there will be many more studies on this important subject.

Belgian patient support group

The Belgian IC patient support group has now been formally set up. Initially it will be working in the Dutch (Flemish) language. Its contact details are as follows:

Interstitiële Cystitis Patiëntenvereniging België (ICPB)

P. Benoitstraat 49, 1800 Vilvoorde, Belgium
email: info@icpb.be

Calendar

The International Continence Society (ICS) annual meeting will be held in Montreal, Canada at the Palais des Congrès de Montréal, August 28 to September 2, 2005.

Website www.opus3.com/ics2005

3rd Conference on Cannabinoids in Medicine, 9-10 September 2005, Leiden, Netherlands, organised by the International Association for Cannabis as medicine (IACM). Email: info@cannabis-med.org Website: www.cannabis-med.org/meeting/leiden2005

EPPOSI European Platform for Patients' Organisations, Science and Industry

6th Workshop on Partnering for Rare Disease Therapy Development, London 25-27 October 2005. "People with Rare Diseases – No Longer Alone in the World".

Website: www.epposi.org

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

Email: info@patientsorganizations.org

website: www.patientsorganizations.org

With best wishes,

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Chairman

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