

International Interstitial Cystitis Patient Network Foundation

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

Newsletter - October 2005

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

In two months' time, the IICPN Foundation will be undergoing a transformation: a change of name and a new website. As from 1 January 2006, the new name will be the INTERNATIONAL PAINFUL BLADDER FOUNDATION, and the new website www.painful-bladder.org.

We believe that the new name reflects the current trend to try and ensure that all patients with a painful bladder condition receive the right diagnosis and appropriate treatment. Our new website will also reflect this approach.

Although the focus of the Foundation will continue to be on painful bladder syndrome/interstitial cystitis, the website will include information on other painful bladder conditions and overlapping conditions such as overactive bladder/incontinence. In other words, the present activities of the IICPN Foundation will continue under the new name, but with a wider scope. Our Foundation has built up a reputation for quality information and we intend this to continue. We also hope to continue to be able to help patients in developing countries, directly and indirectly. As a voluntary, non-profit organisation, our projects abroad are entirely dependent on sponsoring and donations for funding.

We would like to ask all those with a link to our present website to kindly change this as from 1 January 2006.

Patient Definition Survey

For some time now, PBS/IC doctors and researchers around the globe have been endeavouring to agree on new criteria and a new definition for PBS/IC. So far they have been unable to reach international consensus. This patient survey is aimed at giving them a helping hand with a patient's definition. The survey also asks patients to describe the sensation of urgency in their own words.

This survey can be downloaded from the IICPN Foundation website (www.iicpn-foundation.org) in English and Dutch versions. Responders can reply in English, Dutch, French or Spanish. All information received will be treated confidentially and used only for the above purpose.

Kenya

Some months ago, we were approached by James Gathuthi Mwangi from Nakuru, Kenya. James is a bacteriologist and through his work came into contact with IC patients. He decided to form a support group to help patients and to try to raise awareness in Kenya (IC East Africa Support Group, Nakuru Chapter). He contacted some of the IC patient organisations for help. A big problem is that he has no computer of his own and can only communicate through a cyber café. This means that we had to send information by post. The IICPN Foundation sent him several parcels of leaflets, articles, books and anything else that might possibly be useful. We asked a number of other organisations to send material and the COB Foundation was one that willingly responded with useful material, including their new video. James told us that he would ask one of the doctors with video equipment to allow him to view it. Raising awareness in Kenya is quite a problem since there are few urologists in the country and reaching them requires extensive travel. Nevertheless, James Gathuthi Mwangi has made a start. But he needs help, including some financial help for very basic costs. Is there any organisation or individual who has contacts in Kenya who could provide him with help in any shape or form? His email address is: jgmwangi2003@yahoo.com. His address: P.O. Box 16521, Nakuru 20100, Kenya. He has a daunting task and all support will be welcome.

Ghana

The tragic death of three urologists in a car accident in Ghana in the last week of August left the entire country with only eight urologists - including a seriously injured survivor of the crash - and innumerable patients unable to have treatment or undergo surgery. This underlines the urgent need for more specialists to be trained in African countries.

France

The French support group (ci_france@hotmail.com) is working very hard to raise awareness in France. They hold regular meetings, have a revamped website <http://orpha.net/associations/AFCI/cgi-bin/> and a regular newsletter. The September newsletter includes excerpts from the PhD thesis presented in April 2005 in Paris by Florence Ravel entitled "Vivre avec la cystite interstitielle". The newsletter also provides details of a useful site on pudendal pain for French-speakers: <http://pageperso.aol.fr/nerfpudendal/>, the site of the Association des Malades d'Algies Pudendales.

Denmark

The Danish IC support group has a new committee and president: Nanna Toernquist, email nt@dbb.dk. We wish them all every success.

Public Toilets

It was very alarming to hear a short while ago on the BBC News that London is closing down many of its public toilets! A development that the World Toilet Organization (www.worldtoilet.org) cannot be too happy about! This affects not only PBS/IC patients, but all people suffering from urinary or faecal urgency/frequency and incontinence and also all people with stomas who need to empty them, not to mention

parents with children who cannot wait and babies whose nappies need changing! We need to see more public toilets not fewer! The city of Shanghai has been taking this very seriously and setting up designer public toilets around the city. However, in many developing countries, there may be no toilets at all or such dirty public conveniences that people avoid using them. Even in people without urinary disorders, suppression of urination can lead to kidney and bladder diseases. Refraining from drinking so as not to need to use a toilet when away from home can result in dehydration, especially in hot countries.

Did you know that November 19th 2005 is World Toilet Day?

IC support groups have the task of ensuring that local and national authorities are reminded of their responsibility to provide public toilets for everyone (not just men) and to keep them clean!

ICS conference

A report on the annual conference of the International Continence Society (ICS) in Montreal, 28 August – 2 September 2005 can be found on our website (www.iicpn-foundation.org). This includes a review of relevant abstracts, posters and presentations. The ICS now has a pack of fact sheets which includes one on painful bladder syndrome/IC. This will help to raise awareness.

The next ICS conference will be held in Christchurch, New Zealand (www.ics2006.co.nz) and will hopefully be an opportunity for the IC support groups in Australia and New Zealand to increase awareness of both PBS/IC and their patient support organisations.

IACM 3rd Conference on Cannabinoids in Medicine

This very interesting international scientific conference on medicinal cannabis was organised by the International Association for Cannabis as Medicine (www.cannabis-med.org). A full report on the conference, selected presentations and background information about cannabis and hemp is available on the IICPN Foundation website (www.iicpn-foundation.org). The conference abstract book can also be downloaded [here](#).

Book review

Clinical Manual of Incontinence in Women

Editors: P. Abrams, W. Artibani, L. Cardozo, S. Khoury, A. Wein

This very user-friendly book (77 pages) based on the reports of the 3rd International Consultation on Incontinence provides a clear explanation of Basics (such as how the urinary tract works), Evaluation, Treatment and Management Strategy, with lots of pictures to make it all much more understandable. Although intended for health professionals, it is very readable and useful for support group leaders and those writing patient material in any area related to the urinary tract.

Published by Health Publications

ISBN 0-9546956-3-1

For further information contact: editions21@wanadoo.fr

Selected new scientific literature

The section on our website on selected new scientific literature is regularly updated with links to PubMed abstracts where available

(www.iicpn-foundation.org). Just a small selection is mentioned in this newsletter, for more new literature refer to the website.

Painful bladder syndrome/interstitial cystitis.

Rosamilia A, Best Pract Res Clin Obstet Gynaecol 2005 Sep 19; Epub ahead of print.

Painful Bladder Syndrome/Interstitial Cystitis by Anna Rosamilia MD is an Epublication ahead of print. A clear 17 page review of the current situation with PBS/IC.

Safety and efficacy of concurrent application of oral pentosan polysulfate and subcutaneous low-dose heparin for patients with interstitial cystitis.

Van Ophoven A, Heinecke A, Hertle L. Urology 2005;66:707-11

The authors conclude here that the concurrent administration of low-dose heparin and oral PPS appears to be a safe and efficacious treatment modality. Dr A. van Ophoven mentioned to us that the subcutaneously administered heparin appears to be effective in some patients on its own.

Is the potassium sensitivity test a valid and useful test for the diagnosis of interstitial cystitis? Hanno P. Int Urogynecol J Pelvic Floor Dysfunct 2005;16:428-9

and

Argument for the use of the potassium sensitivity test in the diagnosis of interstitial cystitis. Parsons CL. Int Urogynecol J Pelvic Floor Dysfunct 2005;16:430-1

These two articles are a pro/con discussion on the controversial potassium sensitivity test with C.L. Parsons in favour and P. Hanno against.

NVA information on vulvodynia

The National Vulvodynia Association in the USA (www.nva.org) is a wonderful source of information on this very difficult condition. The Vulvodynia Guidelines – a guide to the treatment of vulvodynia and the online Vulvodynia Teaching Programme for health professionals are welcome additions to their already extensive resources. We have a link on our website to each of these items.

IX International Symposium on Sjogren's Syndrome

The IX International Symposium on Sjögren's Syndrome will be held 27-29 April 2006, in Washington DC, USA. This symposium will be chaired by Dr Philip C. Fox of the Sjögren's Syndrome Foundation in the USA which will also be hosting this scientific conference. The proposed programme reflects the significant research progress in Sjögren's since the last international symposium was held in Japan in 2002. For further information on this international conference:

pfox@sjogrens.org, website: www.ISSSonline.org

The programme for ISSS is now available on this site.

Sjögren's information on IICPN site

It is perhaps also useful to give a reminder here that we can provide both patients and health professionals with detailed information on

PBS/IC in association with Sjogren's syndrome. The IICPN Foundation website has extensive resources on Sjögren's syndrome. Chapter 5 of the book on Sjögren's syndrome by Dr Joop P. van de Merwe dealing with treatment has now been revised to include the latest information on NSAIDs. See IC & Associated disorders.

International Alliance of Patients' Organizations (IAPO) Global Patients Congress

IAPO will be organising its next Global Patients Congress, based on the theme "Together we can..." in Barcelona, Spain 22-24 February 2006. This congress is for member organisations. Further information about the congress or about becoming a member organisation can be obtained from:

Email: info@patientsorganizations.org,
website: www.patientsorganizations.org

Poland – 4th Warsaw Seminar on Neurourology

A scientific seminar is to be held in Warsaw, Poland on nocturia, overactivity and pain – symptoms or syndrome. The interesting programme with several presentations on PBS/IC and a round table discussion is being organised by Professor Andrzej Borkowski and Dr Piotr Radziszewski on 3 December 2005 at Sofitel Victoria Hotel, Warsaw. For further information:

Email: neurouro@remedy.com.pl.
Website: <http://neurouro.remedy.com.pl>

2nd Pan-Arab Continence Society Congress

The 2nd Pan-Arab Continence Society Congress to be held in Dubai, United Arab Emirates, 22-24 December 2005, also includes a state of the art presentation on the management of interstitial cystitis. Further information: info2005@pacsoffice.org. www.pacsoffice.org.

With best wishes,

Jane Meijlink

Chairman

International IC Patient Network Foundation
www.iicpn-foundation.org

From 1 January 2006:

INTERNATIONAL PAINFUL BLADDER FOUNDATION
www.painful-bladder.org

Burgemeester Le Fevre de Montignylaan 73
3055 NA Rotterdam
The Netherlands
email: iicpn@dds.nl, ipbf@dds.nl

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