

# International Painful Bladder Foundation

*The IPBF is a voluntary non-profit organization for interstitial cystitis/ painful bladder syndrome*  
[www.painful-bladder.org](http://www.painful-bladder.org)

## **IPBF E-Newsletter, Issue 13, August 2008**

An IPBF update for IC/PBS patient support groups, country contacts, healthcare professionals and friends around the world.

### **NIDDK INTERNATIONAL SYMPOSIUM: “DEFINING THE UROLOGIC CHRONIC PELVIC PAIN SYNDROMES - A NEW BEGINNING”, 16-17 JUNE 2008, BETHESDA, USA.**

The past eight months have been one long round of intensive brainstorming meetings worldwide discussing definitions, criteria and terminology for interstitial cystitis/painful bladder syndrome. However, despite there being several new definitions and numerous name variations including interstitial cystitis, painful bladder syndrome, bladder pain syndrome, hypersensitive bladder syndrome and multiple different combinations, there is no international consensus on either definition or name.

You may indeed be asking yourself why it should apparently be such a difficult task? Why no global consensus? One difficulty is possibly because IC patients are all very different and whatever name or definition you choose, it seems that there is always going to be one group of patients that doesn't fit in. A further problem is that the IC community is spread all round the world, in many different countries with very different medical, social and ethnic cultures. What is culturally appropriate in one part of the world may be considered unsuitable in another. Above all, we still know very little about interstitial cystitis. The lack of concrete evidence means that everyone has his or her own perceptions about this still enigmatic disorder.

The NIDDK symposium held in Bethesda, USA, in June - a follow-up to the meeting in Baltimore in December 2007 - highlighted the fact that, despite a great deal of research into IC in the past years, we are still no closer to discovering the cause or causes of this condition. Not only is there no cure in sight, there is not even a treatment that is effective for all patients, and treatment is still largely based on trial and error. This is devastating for the patients who may never find an adequate treatment, and is economically disastrous. “Trial and error” treatment costs money, often at the expense of the patient. With many patients around the world without any medical insurance, treatment – even if it is available - becomes a luxury they cannot afford.

### **New Approach by NIDDK**

The NIDDK therefore decided that since the old approach to research was clearly not producing concrete results, a new approach was needed. They are now looking at

both interstitial cystitis (IC) and chronic prostatitis (CP/CPPS) in a wider holistic context, incorporating the more common related disorders and exploring in more detail the relationships and overlaps with these co-existing disorders. This symposium was the final brainstorming session before the NIDDK produces a draft definition of IC/PBS for research purposes and specifically the Multidisciplinary Approach to the Study of Pelvic Pain (MAPP) multi-centre project which is currently at the starting blocks.

The NIDDK symposium in Bethesda was attended by around 140 delegates from the USA and abroad. This included experts in urology, gastroenterology, internal medicine, rheumatology, epidemiology, behavioural science, anaesthesiology, pathophysiology, nursing as well as representatives from research centres, health organizations, the pharmaceutical industry and patient advocates not only from the IC world but also related disorders.

A review of this meeting and selected speakers is available on our website: [http://www.painful-bladder.org/pdf/2008\\_NIDDK\\_Bethesda.pdf](http://www.painful-bladder.org/pdf/2008_NIDDK_Bethesda.pdf)

### **Patient Panel in Bethesda**

The NIDDK had also kindly allowed time in the tight schedule for a patient advocacy panel session moderated by Wayne Shields from the Association of Reproductive Health Professionals, with panel members Barbara Gordon (Interstitial Cystitis Association USA), Christin Veasley (National Vulvodynia Association USA), Jane Meijlink (International Painful Bladder Foundation), Rae Marie Gleason (National Fibromyalgia Association USA) and Mike Hennefert from the Prostatitis Foundation, USA.

Key messages from this patient panel included:

- Ultimately, the work of researchers, educators, providers and patient advocates is about helping the patient to feel better. The panel felt that this important goal should not be lost sight of.
- The advocacy community is a key partner to the research community and helps facilitate research: we all have important work to do together. The patient organizations are a potential mine of information – cooperation in research projects can make good use of this.
- It is essential to provide education for multiple disciplines and specialities. It is not enough to simply raise awareness in the urology world. While more awareness of associated disorders has to be created among urologists, awareness of IC has to be raised among specialists working in the field of associated disorders. We also have to ensure that those participating in multidisciplinary teams have more than just a superficial acquaintance with IC.
- Research and decision-making should take account of the different social, medical and ethnic cultures around the world. Many people – doctors and patient advocates – are unable to attend international meetings due to lack of money. Consequently their voice is seldom heard and if heard is seldom taken into account.

### **A few additional patient concerns in Bethesda**

A further concern for patients is that we need to make sure that the current heavy focus on pain does not mean that the all-important symptoms of urgency and frequency in IC patients are not swept under the carpet out of sight. This is not a pain-only disease and every patient is different. All three key symptoms: pain, urgency and frequency are equally important.

While we are fully aware that some IC patients need help with coping with the impact of the disease on their lives, some patient advocates were rather concerned about too much focus on 'psychiatric' issues from some speakers. IC has already been down that avenue in the past and patient advocates had to fight for years to shake off the old image of 'hysterical women' and 'all in the mind' so as to ensure that IC was at last taken seriously as a disease and treated properly. We have no desire to go back to the dark ages and go through that again.

A summary of this symposium is expected to be issued by the NIDDK around September. We will inform you when this is available.

### **4<sup>TH</sup> INTERNATIONAL CONSULTATION ON INCONTINENCE, 5-8 JULY 2008, PARIS, FRANCE**

The purpose of this 4<sup>th</sup> International Consultation on Incontinence (ICI), attended by 750 medical professionals with a special interest in all aspects of incontinence including Interstitial Cystitis/Painful Bladder Syndrome, involved presentation of the current state of knowledge on 23 topics presented by 23 committees, including Committee 19 on Painful Bladder Syndrome, as well as recommending methods of diagnosis and treatment. Each Committee was asked to assess:

- what we know
- what we think we know
- what we don't know
- what we need to know

A review of the presentation by Committee 19 can be found on our website at: [http://www.painful-bladder.org/pdf/2008\\_ICI\\_%20Paris.pdf](http://www.painful-bladder.org/pdf/2008_ICI_%20Paris.pdf)

### **Successful IPBF info stand at ICI raises question: is sufficient attention really being paid to this topic in medical education?**

We would like to thank the ICI organizers, and especially Mme Monique Dubois, for kindly providing us with complimentary stand space in the most perfect location possible. We were overwhelmed by requests for information about IC! Leaflets, brochures and CDs were flying off the table at an incredible rate. Clinicians are also increasingly seeking information about associated disorders. The upcoming NIH/NIDDK MAPP project has already triggered much interest in this aspect. There is still clearly a huge need by urologists and others for even the most basic information on IC which seems to indicate that insufficient attention may still be being paid to this topic in medical education and/or educational courses. It is indeed possible that the information being provided in educational courses is insufficiently practical for clinicians and particularly those working at grass roots level in countries where the treatment options are limited. A further gap in education is also apparently information on the impact of this disease on the patient and the patient's life. Many urologists and other health professionals are aware of this and want to know more. This impact is huge and often the chance of treatment being successful can partly

depend on the patient's ability to cope. Underestimating the impact of the disease on the patient and the moral support that an IC patient needs can lead to treatment failure and "doctor shopping". Involvement of the patient movement in educational issues relating to the impact on the patient could be useful here. After all, only the patients really understand what this impact is and the support groups have a great deal of knowledge acquired over the years through patient-to-patient contact and counselling.

### **Name issue controversy in Paris**

With the name issue being an exceedingly controversial topic in Paris (the ICI scientific committee wishing to abolish the name IC and replace it with bladder pain syndrome), we had every opportunity for feedback on our stand and it was becoming increasingly clear that doctors outside Europe (and indeed many IC experts inside Europe) do not feel that another change in nomenclature is advisable right now and that it should only be done on the basis of scientific evidence. A typical comment was that repeated name changes will result in the disease itself losing credibility in the eyes of both doctors and patients, let alone the medical insurance companies. This is a very worrying prospect. For the sake of the patients, internationally acceptable solutions need to be sought, at the same time taking full account of the impact on the patients of any change in all countries.

### **What should support groups do?**

Since there is no international agreement about the name and/or changes, patient support groups need not get stressed about this issue, but can simply continue using the name they have always used. This is usually interstitial cystitis but in some cases IC/PBS, the two names that are most commonly in use worldwide, either in English or in translation. The names currently in use in addition to interstitial cystitis are: painful bladder syndrome, bladder pain syndrome and hypersensitive bladder syndrome, either alone or in combination with IC.

### **ESSIC ANNUAL MEETING, 5-7 JUNE 2008, ROME, ITALY**

The European Society for the Study of IC/PBS (ESSIC) held its annual meeting this year in Rome organized by Professor Mauro Cervigni who was - as always - a wonderful host. Four patient representatives attended the open part of this meeting: Barbara Gordon (Interstitial Cystitis Association executive director), Loredana Nasta (President Italian AICI), Jane Meijlink (Chairman International Painful Bladder Foundation) and Lynne van Poelgeest (Chairman of the Dutch ICP). The programme included presentations of research studies and the abstracts of these studies can be found at: [http://www.essic.eu/pdf/2008\\_ESSIC\\_Rome\\_abstracts.pdf](http://www.essic.eu/pdf/2008_ESSIC_Rome_abstracts.pdf). This was followed by an ESSIC course on diagnosis and treatment. The next ESSIC meeting will be held in June 2009 in Göteborg, Sweden.

### **INTERNATIONAL MEETING ON UROGENITAL PAIN UPDATE ON UROGENITAL PAIN: CURRENT ISSUES AND CONTROVERSIES 15-18 August, 2008, Glasgow**

A 2-day meeting was held 15-16 August 2008 at the Glasgow Marriott Hotel, Scotland, organised by the PUGO (Pain of Urological Origin), a special interest group of the International Association for the Study of Pain, (PUGO website:

<http://www.indoorcat.org/pugo/>) with some very exciting speakers on different aspects of urogenital pain. A review of highlights from this meeting can be found on the IPBF website:

[http://www.painful-bladder.org/pdf/2008\\_PUGO\\_Glasgow.pdf](http://www.painful-bladder.org/pdf/2008_PUGO_Glasgow.pdf)

It was emphasized that these urogenital pain conditions do not have a homogenous etiology and that some treatments work well for some patients and not at all for others. So-called phenotyping is therefore urgently needed.

Points made include:

- We need to phenotypically categorize our patients with UCPPS and use phenotypically directed therapy.
- Helplessness, fear and anxiety are typical of the impact on the patient by IC and CP/PPS.
- Dyspareunia should be considered as a pain syndrome not a sexual dysfunction.
- It is time to drop the term “somatization”, because it is conceptually problematic, culturally specific and incompatible with pain science.

## PATIENT NEWS

### Support Groups

Some wonderful newsletters in a variety of languages are now coming from the different support groups around the world for their members, containing useful information about treatment, new developments and new insights. Many of the groups organize meetings or other activities for their members.

A support group is a source of information not only for patients but also for all parties interested in knowing more about IC.

In addition, a support group with patient-to-patient contact and patient-to-patient counselling can play an important role in helping patients to cope with their difficult bladder condition and the impact on their lives. We still hear from patients who thought they were the only person in the world diagnosed with this disease. Contact with other people suffering from the same condition, sharing experiences and learning how to cope from other patients can have a very positive therapeutic effect and help to reduce the anxiety and stress caused by the disease. As the saying goes: a problem shared is a problem halved.

### **Note for health professionals: do your patients have a support group?**

Take a look at our international list of patient support groups and country contacts ([http://www.painful-bladder.org/globalgroups\\_etc.html](http://www.painful-bladder.org/globalgroups_etc.html)) and see if there is one in your country for your patients. If not, perhaps you can help to get one started. A useful way to start these days can be to make a simple website in your own language with information for IC patients and their families about the condition, diagnosis, treatment and associated disorders. It can also be a useful reference point for family doctors who have patients with these symptoms. This will create more awareness and ensure that more patients get referred to the right specialists for diagnosis and treatment. Once this happens, there will then be the possibility of forming a small patient support group.

A simple leaflet about IC is essential. See below.



### **Tip: How to make a first leaflet**

Creating a first leaflet on IC/PBS does not need to be immensely time-consuming. There is plenty of good information available, so make the most of it.

Basic information can be found on our website [www.painful-bladder.org](http://www.painful-bladder.org) (leaflets and brochures are under "IPBF publications"

[http://www.painful-bladder.org/IPBF\\_publications.html](http://www.painful-bladder.org/IPBF_publications.html)) and if you need assistance we are always willing to help.

In addition, the NIDDK has a series of easy-to-read texts on different diseases. There is no copyright on this information. The complete list can be found at:

<http://www2.niddk.nih.gov/HealthEducation/HealthEzToRead.htm>

The simple, very clear text on IC/PBS can be found at:

[http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis\\_ez/index.htm](http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis_ez/index.htm)

Or in the pdf version:

[http://kidney.niddk.nih.gov/kudiseases/pubs/pdf/Interstitialcystitis\\_ez.pdf](http://kidney.niddk.nih.gov/kudiseases/pubs/pdf/Interstitialcystitis_ez.pdf)

All of this can give you useful ideas for your own leaflet in your own language. Take a look at the available information on the NIDDK website and the IPBF website and others, and then put together a simple leaflet in your own language that reflects the medical, social and ethnic culture in your country. This can also be used as a basic first website text and elaborated at a later stage.

### **P.U.R.E. H.O.P.E. Patient Meeting Houston, USA**

Pelvic & Urological Resources & Education, Helping Others with Pelvic-Pain

Everywhere 2008 Pelvic Health Patient Education Day

PURE HOPE will be holding a patient conference on Saturday, September 13, 2008 ,

8.30 am to 4.30 pm, registration from 8.00 to 8.30, at the Holiday Inn near The

Galleria, 3131 West Loop South, Houston TX 77027. Speakers include Drs Michael Pezzone, Sandra Hurtado, Peter Lotze, Christopher Smith and Theoharis

Theoharides. Registration can take place online via [www.pure-hope.org](http://www.pure-hope.org) or phone 281-500-4656.

### **Australia**

Alice Terry has retired as contact person for the Australian IC support group. The new contact person and editor of the Australian IC newsletter "In Contact" is Katya Buc. Her email address is [katyabuc\[at\]hotmail.com](mailto:katyabuc[at]hotmail.com). The new ICSG mailing address is: P.O. Box 144, Richmond, VIC 3121, Australia.

### **France**

In their newsletter of July 2008, the Association Française de la Cystite Interstitielle (AFCI), chaired by Françoise Watel, announced the publication of a French translation of a German book (2<sup>nd</sup> edition, 2007) by Dr Ines Ehmer. The French version is entitled "Infections urinaires, douleurs vésicales au quotidien" and covers both bacterial cystitis and interstitial cystitis. This is the first book on IC published in French. The book can be ordered either from the AFCI or from the publisher:

<http://www.arnette.fr>, reference WO2763.

### **New Zealand**

The New Zealand support group, led by Dot Milne, has produced a new information sheet for general practitioners, suggesting that G.Ps could play a greater role in management of IC patients.

## Leaflets for IPBF international congress booths

The IPBF has a booth or info table at several international urology congresses or IC meetings each year. We include leaflets from many support groups in different languages. If you would like your leaflet with your contact details to be included, please send us some by post.

**EUROPEAN ASSOCIATION OF UROLOGY [www.urologyweek.org](http://www.urologyweek.org)**

Last month, the EAU launched a new website to promote the first European Urology Week, which will be organized from 15 to 19 September 2008. [www.urologyweek.org](http://www.urologyweek.org) is a general public-oriented site aiming to provide the general public with information about urological conditions and when to seek help from a urologist. The site currently includes data about three major disorders - prostate conditions, urinary incontinence and erectile dysfunction - in the form of patient and expert interviews, film footage, background articles, etc. Information on Urology Week activities coordinated by urological societies in their own countries will also be made available and continuously updated. There is also a links section with links to patient organizations and, as you can see, the European IC organizations have been making good use of this PR opportunity. If you have any questions, please contact Lindy Brouwer, Communication Officer, at [l.brouwer@uroweb.org](mailto:l.brouwer@uroweb.org)

## WEBSITES

<http://www.medicine.ox.ac.uk/bandolier/booth/painpag/index.html> The Oxford Pain Internet Site. This website is for anyone with a personal or professional interest in pain and treatment of pain. It provides an excellent overview of everything for analgesia. If you've run out of ideas, you will find more here.

<https://www.reliefinsite.com/> A pain relief website with good information on pain management for patients, healthcare providers and healthcare companies.

<http://www.clinicaltrials.gov/ct2/search> A useful website to take a look at clinical trials in progress. This is a service of the National Institutes of Health in the United States. Type into the search window e.g. interstitial cystitis or painful bladder syndrome or IC/PBS (<http://www.clinicaltrials.gov/ct2/results?term=interstitial+cystitis>).

[http://clinicaltrials.ifpma.org/no\\_cache/en/myportal/index.htm](http://clinicaltrials.ifpma.org/no_cache/en/myportal/index.htm) The IFPMA Clinical Trials Portal. Here you can also search for ongoing clinical trials or the results of completed trials.

Don't forget to take a look from time to time at UroToday's section on IC/PBS/BPS at [www.urotoday.com](http://www.urotoday.com) including conference reports and clinical publications.

## INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN (IASP): CLINICAL UPDATES

*These Clinical Updates can be read in full on the IASP website ([www.iasp-pain.org](http://www.iasp-pain.org)) and can be found under the heading "Publications".*

IASP Clinical Update Volume XVI, Issue 4, June 2008: [Update on Fibromyalgia Syndrome](#) by Marie Adele Giamberardino, MD.

<http://www.iasp-pain.org/AM/Template.cfm?Section=Home&CONTENTID=6420&TEMPLATE=/CM/ContentDisplay.cfm>

A useful update on fibromyalgia, concluding that overall most research supports the hypothesis that FMS originates in the central nervous system. Treatment should involve a multidisciplinary approach, including a combination of pharmacological and non-pharmacological interventions. Antidepressants are recommended because they decrease pain and often improve function. Pregabalin effectively reduces the pain and accompanying symptoms in a significant proportion of FMS patients. According to the author, there are likely to be a number of changes in the coming years in the diagnostic approach to FMS and its management.

IASP Clinical Update Volume XVI, Issue 5, July 2008: Gender differences in responses to medication and side effects to medication by Saowarat Snidvongs, BSc and Anita Holdcroft, MD

<http://www.iasp-pain.org/AM/AMTemplate.cfm?Section=Home&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=6689>

Physiological differences between men and women can potentially affect drug efficacy and the likelihood of side effects. The authors conclude by noting that in future they envisage individualized treatment and medication strategies, with the inclusion of sex and gender as well as physiological and pharmacological variables being the accepted standard.

## 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. In the past year we have seen an increasing number of scientific articles "In Press" 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 access to that specific journal.

### Recent scientific articles include:

#### **The role of cystoscopy in the diagnosis of Hunner's ulcer disease**

Braunstein R, Shapiro E, Kaye J, Moldwin R. J Urol. 2008 Aug 14. [Epub ahead of print]. PMID: 18707698

According to the authors, their data from this study demonstrate that standard clinical evaluation cannot reliably distinguish Hunner's ulcer IC from non-Hunner's ulcer IC. These findings suggest that cystoscopy is necessary to accurately identify patients with Hunner's ulcer. This is significant bearing in mind that many clinicians are currently establishing the diagnosis of IC without cystoscopy and that treatment for these two types of IC differs.

Note: Hunner's ulcer is not in fact an ulcer and has therefore more recently been described as Hunner's lesion or patch.



### **Sites of pain from interstitial cystitis/painful bladder syndrome.**

Warren JW, Langenberg P, Greenberg P, Diggs C, Jacobs S, Wesselmann U. J Urol. 2008 Aug 14. [Epub ahead of print]. PMID: 18707715

Multiple pain sites are common in IC/PBS. In this study the authors hypothesized that careful and systematic description might provide clues to its pathogenesis. They studied 226 patients, two thirds of whom reported multiple pains. They concluded that suprapubic prominence and changes in the voiding cycle are features consistent with but do not prove that the bladder is the pain generator in IC/PBS and the pain sites described by patients are referred from it.

### **Deep dyspareunia: causes, treatments and results**

Ferrero S, Ragni N, Remorgida V. Curr Opin Obstet Gynaecol, 2008 Aug;20(4):394-9  
PMID: 18660692

Deep dyspareunia refers to deep pain on intercourse. It is a form of sexual dysfunction that can significantly affect a patient's quality of life and cause relationship difficulties. A number of disorders can cause deep dyspareunia including endometriosis, pelvic congestion syndrome and interstitial cystitis. The authors suggest that the treatment of deep dyspareunia should be mainly directed to causative factors. However, clinicians should bear in mind that secondary sexual dysfunction can arise from organic pelvic pathology.

### **La cystite interstitielle en 2008.**

Mouracade P, Saussine C. Prog Urol 2008 Jul;18(7):418-25. Epub 2008 May 27.  
PMID: 18602600

This review article in French will be a useful update for all French speakers. It concludes:

- la CI reste une pathologie meconnue par le monde medical et le grand public
- la reconnaissance de la physiopathologie rend les traitements encore empiriques.

### **Interstitial cystitis and systemic lupus erythematosus in a 20-year old woman.**

do Socorro Teixeira Moreira Almeida M, Carvalho LL, Carvalho AG, Almeida JV, Borges E Silva J. Rheumatol Int. 2008 Aug 12. (Epub ahead of print]. PMID: 18696074

This article is a case study of interstitial cystitis occurring with systemic lupus erythematosus. The authors suggest that although the exact association of IC and SLE is as yet undefined, there is evidence suggesting that the IC may be a manifestation of the collagen disease.

The authors note that while corticosteroids may reverse the inflammation of the bladder wall, not all SLE patients with IC respond to treatment with corticosteroids, cyclophosphamide or cyclosporine A, but may respond very well to DMSO bladder instillations. They also believe that recognition of bladder involvement in SLE is important since it may be a partially reversible cause of renal failure in a patient with SLE.

### **[A case of lupus cystitis in a 74 year old woman]**

Article in Japanese.

Yukawa S, Tahara K, Hayashi H, Tsuji S, Shoji A, Tsuboi N. Nihon Rinsho Meneki Gakkai Kaishi. 2008 Jun;31(3):183-9. PMID: 18587230.

This article can be found in full free at:

<http://www.istage.ist.go.jp/article/jsci/31/3/183/pdf/-char/ja/>

This Japanese article (with an English abstract) is one of a series from Japan since lupus cystitis was first reported there by Kato in 1985. In this article the authors summarize the clinical features of 46 past cases and discuss differences with this case.

### **Fibromyalgia syndrome: a relevant recent construction of an ancient condition?**

Perrot S. Curr Opin Support Palliat Care. 2008 Jun;2(2):122-7  
PMID: 18685409

This review article asks: Is fibromyalgia a rheumatic condition related to neurological dysfunction? Studies of neuropathic pain suggest that fibromyalgia probably results from abnormal central pain processing rather than a musculoskeletal abnormality. Fibromyalgia syndrome may represent a common clinical presentation of various pathophysiological disorders. Future studies may identify subgroups related to different pathophysiological mechanisms, thereby leading not only to the development of more specific curative but also preemptive treatments.

### **The destruction of the lower urinary tract by ketamine abuse: a new syndrome?**

Chu PS, Ma WK, Wong SC, Chu RW, Cheng CH, Wong S, Tse JM, Lay FL, Yiu MK, Man CW. BJU Int. 2008 Aug 1. [Epub ahead of print]. PMID 18680495

In this article from Hong Kong, the authors show that a syndrome of non-bacterial IC-like symptoms and contracted bladder can be associated with street-ketamine abuse. Ketamine is used medically as an anaesthetic agent, but has gained in popularity as an illegal recreational drug since users erroneously believe that it is not as harmful as other drugs such as heroin. The effects of ketamine on the urinary tract, hitherto unknown to urologists, were first reported in 2007. This report provides the latest update on the clinical features based on new cases.

### **UPCOMING EVENTS 2008:**

- **International Urogynaecological Association (IUGA) annual conference**  
11-14 September 2008, Taipei International Convention Center, Taipei, Taiwan
- **PURE HOPE – Pelvic Health Patient Education Day**. 13 September 2008, Houston, Texas, USA.
- **International Continence Society (ICS) annual conference**, 20-24 October 2008, Cairo, Egypt, including a Public Forum for patients.

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! INTERNATIONAL PATIENT ADVOCACY IS ESSENTIAL.**

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to continue to carry out its projects and international advocacy and activities. All donations to our global 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, Oxyor bv, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters.

### **The Board of the International Painful Bladder Foundation**

email: [info@painful-bladder.org](mailto:info@painful-bladder.org)

[www.painful-bladder.org](http://www.painful-bladder.org)

*The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) [www.patientsorganizations.org](http://www.patientsorganizations.org) and the European Organization for Rare Diseases (EURORDIS) [www.eurordis.org](http://www.eurordis.org).*

*The International Painful Bladder Foundation does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. Information provided in IPBF emails, newsletters, patient information and website is not medical advice. The IPBF recommends patients to consult their own physician before undergoing any course of treatment or medication.*

*The IPBF endeavours to ensure that all information it provides is correct and accurate, but does not accept any liability for errors or inaccuracies.*

*If you do not wish to receive this newsletter in future, please notify the International Painful Bladder Foundation: [info@painful-bladder.org](mailto:info@painful-bladder.org) with “**unsubscribe**” in the subject bar.*

© 2008 International Painful Bladder Foundation