

International Painful Bladder Foundation

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

IPBF E-Newsletter, Issue 15, January/February 2009

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

CREDIT CRUNCH IMPACT ON PATIENT ORGANIZATIONS

Since many IC/PBS patient support groups in different parts of the world already existed on a miniscule budget, the current worldwide economic recession is likely to have a severe impact on the non-profit patient movement. We would like to take this opportunity of appealing to everyone involved in any way in IC/PBS to consider making a donation – however small – to your local, national or international non-profit patient organization. Every little bit helps. Please do everything possible to ensure that the patient-driven charities can survive the present economic malaise.

THE ALS PELVIC PAIN DIAGNOSTICS & PROCEDURES MEETING: PUDENDAL NEURALGIAS, PELVIC & PERINEAL PAIN IN URO-GYNAECOLOGY 8-9 January 2009, Aix-en-Provence, France

This most interesting conference in France – a country where pioneering work has been done in the field of pudendal neuralgias - was unfortunately affected by heavy snowfalls in the region, with both the airport and railways closed. As a result, some of the speakers and participants were unable to reach the conference in person. This included the IPBF chairman who went by train from Rotterdam to Brussels, could get no further due to train cancellations because of the snow, was then dispatched to Paris in the hope of picking up a train or plane there, but alas ended up being 'repatriated' from Paris back to Rotterdam since all means of transport to the Aix-en-Provence region were cancelled. A pair of skis might have been handier than a train ticket.

However, Dr S. Antolak from the USA amazingly did manage to make it to Aix-en-Provence (albeit in a roundabout way) and gave a presentation on "Urologic Symptoms and Interstitial Cystitis in Pudendal Neuralgias". According to Dr Antolak, take-home messages from this meeting included the following:

- bladder symptoms (such as IC, PBS, retention) can be caused by pudendal neuropathy, Maigne syndrome (Thoracolumbar Junction Syndrome, Posterior Rami Syndrome) and Middle Cluneal Neuropathy;
- the bladder is the end organ responding with neurogenic inflammation to three peripheral neuropathies.
- the focus should change from bladder mucosa to peripheral nerves and spinal cord windup.

Despite the inclement (and inconvenient) weather, the organizers are to be congratulated on producing an excellent and very practical programme covering all

aspects of diagnosis, treatment and epidemiology of pudendal neuralgias and pelvic pain, discussing a wide variety of treatments including osteopathy, physical and manual therapy, botulinum toxin and surgical techniques.

We hope to see far more of these French pioneers presenting their interesting and valuable research and unique practical experience on pudendal neuralgias and pelvic pain at international symposiums in the future. Meeting site:
<http://www.alsmeeting.com/EN/index.html>

ESSIC 2009 ANNUAL MEETING WITH OPEN SESSIONS 4-6 June, 2009, Sweden

The annual meeting of the European Society for the Study of IC/PBS (ESSIC) will be held from 4-6 June 2009 at the Storan Theatre in Göteborg, Sweden. Preliminary information is currently available on the ESSIC website (www.essic.eu). Provisional plans include open sessions for non-members as follows:

Friday 5 June:

10-30-12.00 - Scientific presentations

13.00-17.00 - SYMPOSIUM ON HUNNER'S LESION

Saturday 6 June

09.00-12.00 – Workshop on: HOW TO TREAT BLADDER PAIN, A PRACTICAL APPROACH including: “How to diagnose the confusable disease pudendal neuropathy”.

Further details on registration fees for non-ESSIC members and how to register will be placed on the ESSIC website as and when available.

NEW WEBSITE IN AHMEDABAD FOR INDIAN IC/PBS PATIENTS

A website for IC patients has been launched by the Interstitial Cystitis Center, director Dr Nagendra Mishra, at the Kidney and Urology Hospital in Ahmedabad, India. The IC Center at this hospital is the first in India. This new website is likewise a first IC website initiative in India and provides Indian patients with practical information about diagnosis and treatment in their own country: www.interstitialcystitiscenter.in.

ASSOCIATED DISORDERS:

10TH INTERNATIONAL SYMPOSIUM ON SJÖGREN'S SYNDROME with Patient Workshop, 1-3 October, 2009, Brest, France.

The 10th International Symposium on Sjögren's syndrome is to be held in Brest, France 1-3 October 2009. Details including the provisional scientific programme can be found on the symposium website: <http://www.sjogrensymposium-brest2009.org>

As you will see on the website, patient advocates are very welcome. The organizers state that “for our work in Sjögren's syndrome to succeed, input from the patients is essential. All will be very welcome in Brittany!” They add: “We invite all of the patient associations and foundations to meet in Brest (France, USA, UK, Italy, Brazil, Israel, Japan, etc) to ask the question, ‘How are you doing in your country?’, and to collect information on new approaches to meet our common goals. These representatives will bring back news to their countries”. A special workshop is being organized during the symposium for patient associations in this field.

IC or other patient associations who may wish to attend should contact: Association Française du Gougerot-Sjögren et des Syndromes Secs (AFGS) Symposium Team: afgs.congresbrest@gmail.com

EURORDIS

The annual Eurordis membership meeting will be held 8-9 May 2009, Athens, Greece. For information, please contact anja.helm@eurordis.org. See also website: www.eurordis.org.

Information about European action in the field of rare diseases and EUROPLAN: a joint action for National Strategies and Plans for Rare Diseases in all EU Member States can be found on the Eurordis website:

http://www.eurordis.org/secteur.php3?id_rubrique=1

RARE DISEASES DAY: 28 FEBRUARY 2009

For further information about Rare Diseases Day around the world, take a look at the Eurordis website: <http://www.rarediseaseday.org/>

If you would like to take part, please contact your National Alliance for Rare Diseases or contact Eurordis: rarediseaseday@eurordis.org

IAPO CALLS ON WORLD HEALTH ORGANIZATION (WHO) MEMBER STATES TO PROTECT PATIENTS FROM COUNTERFEIT MEDICAL PRODUCTS

London, UK, 29 January 2009 - The International Alliance of Patient's Organizations (IAPO) recently urged members of the WHO Executive Board and member states to protect patients from counterfeit medical products by taking action to promote awareness of the dangers they pose. This request was at the core of an intervention made by Jeremiah Mwangi, IAPO Senior Policy Officer, addressed to delegates at the 124th session of the WHO Executive Board in Geneva, Switzerland.

Counterfeit medical products pose a very real threat to the lives of patients worldwide, and are one of many threats to the quality and safety of medicines available to patients. IAPO believes that the prevalence and availability of counterfeit medical products highlights the gross inequity in access to safe and effective medical products that exists around the world.

In order to protect patients, IAPO made the following call to delegates: *"In WHO and member states actions to protect the public from counterfeit medical products, we ask you to not only promote awareness of counterfeit medical products among health professionals, but also among patients so that they can be vigilant and report suspect medicines. IAPO believes that it is essential to take comprehensive and coordinated action to communicate the risks of counterfeit medical products to patients, and to keep patients safe."*

IAPO has prioritised the issue of counterfeit medical products as one of many patient safety issues that are a real danger to patients and, with other patients' organizations, can make a substantial contribution to partnerships with other key stakeholders. In the role of information provider, IAPO has produced a toolkit for patients' organizations which includes information to enable patients to identify potential counterfeit medical products and ensure that they acquire medicines that are safe and effective.

The International Medical Products Anti-Counterfeiting Taskforce (IMPACT) estimates that: *“Many countries in Africa and parts of Asia and Latin America have areas where more than 30% of the medicines on sale can be counterfeit.”* This demonstrates in stark terms the need for political commitment and the full energy of those global institutions, designed to protect and promote public health, to combat this problem. This critical public health issue must not be allowed to slip off the agenda.

The full statement is available on the IAPO website:

<http://www.patientsorganizations.org/showarticle.pl?id=983>

IACM 5TH CONFERENCE ON CANNABINOIDS IN MEDICINE IN COLOGNE, GERMANY, ON 2-3 OCTOBER: CALL FOR PAPERS

CALL FOR PAPERS: The programme committee would like to invite you to present your research at the IACM 5th Conference on Cannabinoids in Medicine in Cologne, Germany, on 2-3 October. You may submit your abstract electronically until 15 April 2009 for oral presentations and until 15 June 2009 for poster presentations to info@cannabis-med.org. If your abstract is accepted you will have free access to the meeting. Speakers may ask the IACM for a subsidy of their travel expenses.

For further information about this conference, please contact:

International Association for Cannabis as Medicine (IACM). Am Mildeweg 6, D-59602 Ruethen, Germany, Phone: +49 (0)2952-9708571. Fax: +49 (0)2952-902651. Email: info@cannabis-med.org. <http://www.cannabis-med.org>

FDA APPROVES TOPICAL OXYBUTYNIN CHLORIDE GEL FOR OAB SYMPTOMS

According to HealthDay (28/1/09, Scott Roberts), the FDA has approved an oxybutynin gel 10% (Gelnique™) for topical treatment of the symptoms of overactive bladder (including urgency, frequency). This gel is applied daily to the thigh, abdomen, upper arm or shoulder. The most frequent side effects reported during clinical trials included dry mouth plus local reactions where the gel was applied. However, according to the manufacturer Watson Pharmaceuticals, since it is absorbed via the skin, it is not metabolized by the liver as oral oxybutynin is.

USEFUL FOR IC PATIENTS - LONDON UNDERGROUND TOILET FACILITIES MAP

While browsing the London underground website, we found the following useful information about toilet facilities when you are travelling around London and suburbs. A map of toilet locations is available on the following site page:

<http://www.tfl.gov.uk/assets/downloads/toilets-map.pdf>

Accompanying useful information about toilets can be found on this site page:

<http://www.tfl.gov.uk/assets/downloads/toilet-facilities-useful-information.pdf>

NVA NEWSLETTER

The National Vulvodynia Association in the USA is an extensive source of information for women with all types of vulvodynia and for health professionals treating patients with these conditions. Its newsletter, NVA News, volume XIV, issue 1, Winter 2008,

has a very interesting Q&A interview with Dr Caroline Pukall of Queen's University in Kingston, Ontario, Canada on "Primary and Secondary PVD: Are they different?" PVD stands for Provoked Vestibulodynia, also known as vulvar vestibulitis syndrome. Dr Pukall concludes from the results of their study that women with primary and secondary PVD may possibly differ in some aspects of pain reporting, psychosocial functioning, and genital and non-genital sensitivity. There is also an excellent article in this issue on the impact of PVD on couples by Dr Jennifer Connor who is also a patient as well as a researcher.

Further information about the NVA, how to join and receive the newsletter is available on the NVA website, www.nva.org which is well worth visiting if you are seeking patient or professional information on this complex disease area.

Vulvodynia Treatment Registry

The NVA is also inviting proposals from clinical researchers to develop and then maintain a provider-based Vulvodynia Treatment Registry with the aim of determining a) which treatment(s) is effective for each vulvodynia subtype and b) the biological characteristics of women who benefit from a specific treatment. Please contact Christin Veasley by phone (401-398-0830) or email (chris@nva.org) for further information.

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 online access to that specific journal.

Japanese guidelines for diagnosis and treatment of interstitial cystitis

Homma Y, Ueda T, Ito T, Takei M, Tomoe H. Int J Urol. 2009 Jan;16(1):4-16.

PMID: 19120522

This article is the shortened version of the Japanese Guidelines for an international readership. The full version is available in Japanese. The guideline was developed by the executive members of SICJ (Society of Interstitial Cystitis of Japan), founded in 2001, and endorsed by the Japanese Urological Society (JUA). In this guideline, IC is defined as 'a disease of the urinary bladder diagnosed by three conditions: (i) lower urinary tract symptoms such as urinary frequency, bladder hypersensitivity and/or bladder pain; (ii) bladder pathology proven endoscopically by Hunner's ulcer and/or mucosal bleeding after over-distension, and (iii) exclusion of confusable diseases such as infection, malignancy or calculi of the urinary tract.' The term 'hypersensitive bladder syndrome (HSB)' is suggested for the symptom syndrome associated with IC or IC-like conditions. According to the authors, new treatments for IC will be challenged for efficacy in the future. They also believe that inclusion criteria and efficacy assessment should be standardised to enhance the research process.

This article includes a clinical algorithm intended to guide practitioners in diagnosing and treating patients with IC or a suspicion of IC.

Diagnostic options for early identification and management of interstitial cystitis/painful bladder syndrome

Forrest JB, Moldwin R. *Int J Clin Pract.* 2008 Dec;62(12):1926-34. PMID: 19166439

This is a most welcome "down-to-earth", clearly written review article which clinicians will find very useful, but which is also easily readable by the lay person such as patients and patient advocates and provides a good overview of the current situation. According to the authors, the aims of the article were to discuss options for diagnosing IC, to compare approaches and to encourage early diagnosis of this disorder in the primary care setting. They believe that a thorough patient history, physical examination and laboratory evaluations are keys to the diagnosis of IC, while optional diagnostic approaches may help increase physician confidence in prescribing therapy for this disorder. Although no definitive marker is currently available, there are a number of optional tools to assist in the diagnosis of IC. They conclude that understanding the options available to diagnose IC may result in earlier identification and treatment for some patients.

Evaluation of health-related quality of life in patients with painful bladder syndrome/interstitial cystitis and the impact of four treatments on it.

Sairanen J, Leppilähti M, Tammela TL, Paananen I, Aaltomaa S, Taari K, Ruutu M. *Scand J Urol Nephrol.* 2009 Jan 9:1-8. [Epub ahead of print] PMID: 19137459

This study evaluated a health-related quality of life (HRQoL) questionnaire in 151 PBS/IC patients. The authors concluded that treatment of PBS/IC has obvious effects on quality of life and that the HRQoL questionnaire can be used in evaluating QoL in PBS/IC patients. The questionnaire is appended to the article.

Goal achievement provides new insights into interstitial cystitis/painful bladder syndrome symptoms and outcomes.

Payne C, Allee T. *Neurourol Urodyn.* 2009;28(1):13-7. PMID: 19089894

Using the Goal Assessment Scaling (GAS) concept, the authors used surveys and focus groups to characterize the goals of patients with IC/PBS in order to create a pilot GAS. As the authors explain: "when faced with disorders that present as symptoms rather than signs, the clinician is dependent on patient reports to guide diagnosis and treatment".

It was concluded that patients have individualized treatment goals. GAS holds promise for addressing individuality in a standardized format.

A new instrument developed from this work is being piloted in a multicenter RCT.

The authors also suggest that questionnaires investigating urgency in IC/PBS clarify the definition in a way more applicable to the specific condition. The groups defined **urgency** in IC/PBS as "the need to urinate due to an unpleasant sensation that prevents attention to any other task."

Childhood symptoms and events in women with interstitial cystitis/painful bladder syndrome.

Peters KM, Killinger KA, Ibrahim IA. *Urology* 2009;73:258-62. PMID: 19036420

The aim of this study was to explore the prevalence of recurrent urinary tract infections (UTIs), dysfunctional voiding and bowel elimination difficulties experienced in childhood and adolescence in adult women with interstitial cystitis/painful bladder syndrome and community controls, since the relationship between dysfunctional voiding and bowel symptoms in early life and the development of IC/PBS later on is not clear. Furthermore, the authors comment that reliance in the past on the NIDDK

research criteria has hampered early identification of the disease and contributed to a lack of published reports of IC in children. In this study, recurrent UTIs in childhood and urgency in adolescence emerged as the early life symptoms/events most strongly associated with the development of IC/PBS later on. The authors believe that it is important to observe the development of symptoms over the long term and identify factors in early life and that this could contribute to our understanding of the natural history of this disease and hopefully lead to earlier diagnosis, more effective treatment and prevent disease progression.

Prevalence of Painful Bladder Syndrome in older women

Lifford KL, Curhan GC. *Urology*. 2008 Dec 30 [Epub ahead of print] PMID: 19118882
This study into the prevalence of and symptoms associated with painful bladder syndrome in a population of older women concluded that PBS is a common condition in women and the prevalence of PBS increases with age.

Evaluation of urgency in women, with a validated Urgency, Severity and Impact Questionnaire (USIQ).

Lowenstein L, Fitzgerald MP, Kenton K, Hatchett L, Durazo-Arvizu R, Mueller ER, Goldman K, Brubaker L. *Int Urogynecol J Pelvic Floor Dysfunct*. 2008 Nov 20. [Epub ahead of print] PMID: 19020786

This study concerned the development of a validated, patient-oriented questionnaire to assess urgency and associated impact on life in overactive bladder (OAB) patients. Open access article.

<http://www.springerlink.com/content/k76603103h7563q7/fulltext.pdf>

Click the title above for the full article (it is distributed under the terms of the Creative Commons Attribution Noncommercial License which permits any noncommercial use, distribution, and reproduction in any medium, provided the original author(s) and source are credited)

Treatment of refractory interstitial cystitis/painful bladder syndrome with CystoProtek - an oral multi-agent natural supplement.

Theoharides TC, Kempuraj D, Vakali S, Sant GR. *Can J Urol*. 2008 Dec;15(6):4410-4. PMID: 1904649

The authors conclude from this open-label, uncontrolled study with 250 refractory (male and female) IC/PBS patients that prospective randomized trials of such dietary supplements are warranted and that food supplements targeting the bladder GAGs may be a useful addition to the treatment arsenal.

Interstitial cystitis: bladder pain and beyond.

Theoharides TC, Whitmore K, Stanford E, Moldwin R, O'Leary MP.

Expert Opin Pharmacother. 2008 Dec;9(17):2979-94. PMID: 19006474

This article reviews the pathogenesis and treatment of interstitial cystitis with emphasis on new pathogenetic trends and therapeutic modalities. The authors believe that subgroups of IC patients with either distinct bladder pathology (e.g. increased mast cells) or co-morbid diseases (e.g. fibromyalgia) may respond differently to specific treatments. They state that many studies have a poor description of IC patients, with variable inclusion and exclusion criteria. The authors are of the opinion that a number of key areas have failed to be seriously studied.

New cystoscopic diagnosis for interstitial cystitis/painful bladder syndrome using narrow-band imaging system.

Ueda T, Nakagawa M, Okamura M, Tanoue H, Yoshida H, Yoshimura N. Int J Urol. 2008 Dec;15(12):1039-43. Epub 2008 Nov 13. PMID: 19054176

The aim of this study was to develop an IC/PBS diagnostic method using a cystoscope with a narrow-band imaging (NBI) system. The authors concluded that examining the bladder mucosa with a flexible cystoscope with the NBI system makes it possible to easily detect bladder mucosa ulcers (lesions) and areas with angiogenesis. The procedure is less invasive and lower in cost than the conventional hydrodistension.

Intravesical alkalinized lidocaine (PSD597) offers sustained relief from symptoms of interstitial cystitis and painful bladder syndrome.

Nickel JC, Moldwin R, Lee S, Davis EL, Henry RA, Wyllie MG. BJU Int. 2008 Nov 13. [Epub ahead of print]. PMID: 19021619

The purpose of this preliminary study was to assess the immediate and sustained relief of the symptoms of IC/PBS after a consecutive 5-day course of intravesical alkalinized lidocaine (PSD597) and to characterize the pharmacokinetics of single and multiple doses of intravesical PSD597 in a subgroup of patients. The authors concluded that this treatment was effective for providing sustained improvement of IC/PBS symptoms beyond the acute treatment phase. The drug was safe, well-tolerated and devoid of the systemic side-effects often experienced with oral drugs. Long-term studies are needed to determine the optimum regimen to maintain this favourable treatment effect.

Treatment of interstitial cystitis with hydrodistention and bladder training.

Hsieh CH, Chang ST, Hsieh CJ, Hsu CS, Kuo TC, Chang HC, Lin YH.

Int Urogynecol J Pelvic Floor Dysfunct. 2008 Oct;19(10):1379-84. Epub 2008 May 22. PMID: 18496634

This study from Taiwan aimed to evaluate the efficacy of hydrodistention (HD) and bladder training for interstitial cystitis in 361 patients from 1997 to 2006. In this group of patients, use of HD + bladder training was found to give long-term symptomatic remission among IC patients.

Recurrent urinary tract infections and bladder dysfunction in systemic lupus erythematosus.

Duran-Barragan S, Ruvalcaba-Naranjo H, Rodriguez-Gutierrez L, Solano-Moreno H, Hernandez-Rios G, Sanchez-Ortiz A, Ramos-Remus C. Lupus. 2008;17(12):1117-21. PMID: 19029280

Systemic lupus erythematosus (SLE) is an autoimmune disease which involves multiple organ systems, leading to chronic inflammation and tissue damage. Previous studies (including studies on IC in SLE patients) have shown that SLE patients have more urinary symptoms than the general population. Causes of bladder dysfunction in SLE include medication (cyclophosphamide), immune complex-mediated interstitial cystitis (lupus cystitis) and neurogenic dysfunction. The authors believe that milder cases of lupus cystitis may be more prevalent than previously thought.

Article in Spanish:

**Enterocistoplastia por cystitis intersticial. Resultados diferidos.
[Enterocystoplasty for interstitial cystitis: Deferred results]**

Astroza Eulufi G, Velasco PA, Walton A, Guzman KS. Actas Urol Esp. 2008 Nov-Dec;32(10):1019-23. PMID: 19143294

The purpose of this study was to evaluate the results of a series of IC patients who had failed to respond to conservative treatment and who underwent enterocystoplasty surgery. They concluded: "La enterocistoplastía es una técnica útil para el manejo de ritmo miccional, aumentando la capacidad vesical, en pacientes que padecen cystitis intersticial y que son refractorios al tratamiento médico. En el seguimiento en el tiempo los pacientes permanecen con mejoría significativa de sus síntomas y disminución de su frecuencia miccional. Debemos destacar eso si, que es una técnica no exenta de complicaciones las cuales pueden ser de alto riesgo."

While this form of surgery can have a good effect in some patients by increasing bladder capacity and reducing frequency, it is not without the risk of complications which may be serious.

The free full text of this article in Spanish is available at:

<http://www.actasurológicas.info/articulo/articulo.asp?code=/32/1019>

Mechanisms of disease: Endometriosis.

Bulun SD. N Engl J Med 2009;360:268-79

Review Article

Endometriosis is an estrogen-dependent inflammatory disease affecting 5-10% of women of reproductive age in the USA. Its defining feature is the presence of endometrium-like tissue in sites outside the uterine cavity. The main clinical features are chronic pelvic pain, pain during intercourse and infertility.

This is a useful review of current knowledge.

REMINDER: KEEP UP-TO-DATE WITH ONGOING CLINICAL TRIALS

Reminder: keep up-to-date with IC/PBS clinical trials in progress around the world. Go to the World Health Organization clinical trials portal at <http://www.who.int/ictrp/en/> or go directly to the search for trials page: <http://www.who.int/trialsearch> and type in either interstitial or painful bladder syndrome. You will then find all trials summarized and see which trials are recruiting patients.

Alternatively go to the USA site: <http://clinicaltrials.gov>, type in interstitial cystitis or painful bladder syndrome and you will find studies in progress, completed, terminated or about to recruit in the USA. To go directly to the IC trials page: <http://clinicaltrials.gov/ct2/results?term=interstitial+cystitis>

UPCOMING EVENTS 2009:

SUNA Annual Symposium - Incontinence and Pelvic Floor Disorders

March 11-14, 2009, Hyatt Regency, San Francisco, CA, USA

WIP2009 - 5th World Congress World Institute of Pain

13-16 March 2009, New York, NY, USA

24th European Association of Urology (EAU) Congress

17-21 March 2009. Stockholm, Sweden

21st Annual EuroMeeting of the Drug Information Association (DIA)

23-25 March 2009, Berlin, Germany

American Urological Association (AUA) annual conference

25-30 April 2009, Chicago, USA

Eurordis Membership Meeting

8-9 May 2009, Athens, Greece

ESSIC Annual Meeting

4-6 June 2009, Göteborg, Sweden

World Continence Week

22-28 June 2009

10th International Symposium on Sjögren's Syndrome

1-3 October, 2009, Brest, France.

30th Congress of the Société Internationale d'Urologie (SIU)

1-5 November 2009, Shanghai, China

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 TO CONTINUE ITS INTERNATIONAL PATIENT ADVOCACY AND AWARENESS CAMPAIGN AROUND THE GLOBE IN 2009.

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 Astellas Pharma bv, Oxyor bv, Bioniche Pharma Group Ltd and private donors for their greatly appreciated financial support for our foundation, projects, patient advocacy, website and newsletters for the year 2009.

The Board of the International Painful Bladder Foundation (IPBF)

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.

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.

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