

International Painful Bladder Foundation

The IPBF is a voluntary non-profit organization focused on interstitial cystitis/bladder pain syndrome/hypersensitive bladder/Hunner lesion
<https://www.painful-bladder.org/>

IPBF e-Newsletter Issue 65, May 2023

An IPBF update for patient support groups, healthcare professionals and friends around the world in the field of interstitial cystitis, bladder pain syndrome/painful bladder syndrome, hypersensitive bladder, Hunner lesion, ketamine cystitis, chronic pelvic pain and associated disorders.

This issue of the IPBF e-Newsletter includes the following topics:

- IPBF Research Update online link
- ESSIC IC/BPS Congress to be held in New York 6-8 July 2023
- Review of EAU Congress 2023 Milan, Italy - Patient Day “Cystitis” session
- Review of EFIC webinar on Chronic Primary Pain in ICD-11, 28 April 2023
- Review of AUA 2023 – 28 April to 1 May - Chicago
- Books/Publications:
 - ICI 7th Edition with Chapter 18 on IC/BPS
 - StatPearls: amitriptyline, interstitial cystitis and dysuria
 - Clinical and Experimental Rheumatology Journal Supplement on Sjögren’s
- Web Information
- Overview of Upcoming Events
- Donations & Sponsoring

IPBF RESEARCH UPDATE ONLINE LINK

To facilitate downloading of the Research Update, please note we have now placed the **IPBF eNewsletter** and **IPBF Research Update** in separate pdf files online. Both can be accessed via the IPBF home page: <https://www.painful-bladder.org/>

The **Research Update May 2023** can also be accessed directly at:

https://www.painful-bladder.org/pdf-2/2023-05_ResearchUpdate.pdf

Today we are seeing far more open access papers than in the past and this is particularly useful for patient advocates and their organizations who wish to learn more about scientific developments so as to equip them better for patient participation in research projects or patient advisory panels and of course to help educate the members of their support groups. We also now include so-called “Preprints” where relevant. These are preliminary reports of work that have not been certified by peer review. They should therefore not be relied on to guide clinical practice or health-related behaviour.

(See <https://www.medrxiv.org/content/about-medrxiv> for further information about Preprints)

For those with an interest in guidelines and classifications, we have included a new paper on the World Health Organization’s (WHO) international classification system with proposals for

changes by the authors to bring about a harmonized, multifactorial definition of pain in all three classification systems:

[TOWARDS HARMONIZING THE CONCEPTS AND DEFINITIONS OF PAIN IN THE WORLD HEALTH ORGANIZATION'S FAMILY OF INTERNATIONAL CLASSIFICATIONS](#)

Michiel F Reneman, Melissa Selb, Beatrice Korwisi, Antonia Barke, Reuben S Escorpizo, Samson W Tu, Rolf-Detlef Treede. Pain. 2022 Dec 22. doi: 10.1097/j.pain.0000000000002854. Online ahead of print. PMID: 36728950 DOI: 10.1097/j.pain.0000000000002854 (Open Access article)

WHO classifications are not easy to understand, but they do play an important role in our healthcare systems. There is, however, a video which explains in simple terms what it is all about and what the new proposals are in relation to chronic pain. One of the aims is to improve access to multimodal and interdisciplinary pain treatment.

It is therefore important for everyone in the IC/BPS world to keep a close eye on what is written and proposed in these classifications about chronic pain and especially in relation to bladder pain so as to ensure that this really matches up to the real disease and symptoms as experienced by IC/BPS patients.

The video link can be found at:

https://cdn-links.lww.com/permalink/pain/b/pain_2023_02_02_reneman_pain-d-22-00623_sdc1.mp4

ESSIC IC/BPS CONGRESS TO BE HELD IN NEW YORK 6-8 JULY 2023

After several postponements due to Covid, the long-awaited ESSIC congress is to be held 6-8 July 2023 in New York, USA. Meeting Chair is the ESSIC vice-president Professor Robert Moldwin. The venue will be [Lenox Health Greenwich Village](#), a state-of-the-art medical complex centrally located in Manhattan, New York.

The meeting will include keynote lectures, debates, panel discussions etc on IC/BPS by top speakers, as well as networking events. Check the ESSIC Congress website to keep updated and to subscribe to the ESSIC 2023 newsletter: www.essicmeeting.eu where you will find details of the scientific programme and how to register. For queries, contact: essic@defoe.it

REVIEW OF EAU CONGRESS 2023 MILAN, ITALY - PATIENT DAY "CYSTITIS" SESSION

EAU Patient Office

The EAU Patient Office was set up in 2021 and is therefore still in a relatively early stage of its development. Nevertheless, this Patient Office now has a Chair, Prof. Eamonn Rogers, and more recently a Patient Office Board. It also has a Patient Advocacy Group (EPAG), see <https://patients.uroweb.org/patient-advocacy/>. EAU Patient Information can be found at <https://patients.uroweb.org>. The EAU now also has a special membership category for patient advocates: Patient Advocate Member (PAM).

EAU 23 Patient Day: Friday 10 March

This was the third EAU Congress Patient Day where patient advocates can make their voice heard and also present work at the Patient Poster Session.

One session of particular interest to us concerned Cystitis – with two presentations focusing on IC/BPS - aimed at enabling delegates to differentiate between the different types of cystitis and their treatment options, in addition to gaining insight into a patient's care pathway. All presentations were recorded and are available as webcasts on the EAU website: <https://urosourc.uroweb.org/search?sessionId=13548>.

IPBF chair Jane Meijlink spoke on the topic of Taxonomy and Nomenclature, terms that cover the whole field of standard terminology, definitions, criteria and classification, the history of which in the field of IC/BPS could fill a bookcase! Since the purpose of standard terminology is to identify and accurately describe a disease or disorder, guide research, diagnosis and treatment, enable information and research to be shared globally without confusion, facilitate consistency in electronic systems, for data retrieval, healthcare reimbursement, benefits etc, and also to enable patients to recognise their diagnosis and seek relevant information, the speaker concluded that these aims have in no way been achieved and all we have is confusion worldwide! She added that in today's world, it seems irresponsible and certainly patient-unfriendly to keep changing the name of a disease. It is time for global consensus on both the name and the definition + a truly patient-centric approach.

Anna De Santis, IC/BPS patient from Italy and a representative of both eUrogen and AICI, gave the patient lived-experience point of view, speaking very movingly on a patient's care pathway experience from diagnosis to deciding on treatment. She emphasized that the symptoms of IC can be extremely debilitating. Trips to the bathroom throughout the night can lead to sleep deprivation, resulting in severe depression as well as extreme fatigue. The intractable pain can lead to suicidal ideation and she noted that 10 AICI members had committed suicide in the past 20 years. Apart from the question as to whether IC is a rare disease or not, she emphasized that in her experience doctors who know about this disease are very rare indeed! In Italy, the government recognised IC as a rare disease in 2001 and provides patients with free medical care! Patients in many other countries (of the EU!) do not have this luxury!

Dr Gernot Bonkat from Basel discussed urological infections, the issue of increasing antibiotic resistance, classification of UTIs, complicated and uncomplicated UTIs, the different UTI organisms, and how to diagnose and treat while reducing use of antibiotics. However, he emphasized that non-use of antibiotics can lead to treatment failure and febrile UTI. Like IC/BPS, there is no one-size-fits-all approach in UTIs. Nevertheless, antimicrobial agents remain the cornerstone of treatment for uncomplicated cystitis. Many women suffer from recurrent UTIs. Antimicrobial prophylaxis reduces the rate of rUTIs in pre- and postmenopausal women but should be carefully considered due to the worldwide emergence of antimicrobial resistance.

REVIEW OF EFIC WEBINAR ON CHRONIC PRIMARY PAIN IN ICD-11, 28 April 2023

On 28 April, the IPBF chair attended a webinar organised by EFIC on chronic primary pain where the aim was to give an overview of the definition and new classification under ICD-11 as well as provide information on the assessment and management of chronic primary pain. Panellists were Prof. Rolf-Detlef Treede, Heidelberg University, Dr Beatrice Kowisi, Philipps-University Marburg and Prof. Paul Cameron, EFIC Advocacy Committee Chair.

Online attendees were able to actively ask questions via the Q&A box and the IPBF asked a number of questions regarding how IC/BPS fits into chronic primary pain classification where it is referred to as chronic primary bladder pain syndrome. One had the distinct feeling that it does not really fit in, that it might be a square peg in a round hole, that there are many unanswered questions and that we have to be exceedingly alert as to where all of this may be leading from the point of view of IC/BPS.

The definition of chronic primary pain for ICD-11 is as follows:

Chronic primary pain is defined as one or more body systems (e.g. nervous, musculoskeletal and gastrointestinal systems) and in any body site (face, low back, neck, upper limb, thorax, abdominal, pelvis and urogenital region) or in a combination of body sites (e.g. widespread pain) that:

1. persists or recurs for longer than 3 months
2. is associated with significant emotional distress (e.g. anger, anxiety or depressed mood) and/or significant functional disability (impacts on one's activities of daily life, hobbies and participation in social roles)
3. and the symptoms are not better accounted for by another diagnosis.

Point 3 indicates that the IC/BPS world needs to develop better methods of diagnosing a defective, damaged, leaky, hypersensitive urothelium in non-Hunner lesion patients leading to pain in the bladder + urinary symptoms. If we do not, this specific group of patients - where little or nothing may be visible on current cystoscopy - are likely to be classified as pain-only patients, with no attention paid to urinary symptoms and a risk of non-reimbursement of intravesical treatment. Furthermore, this can also lead to research being diverted away from urinary symptoms.

This was a very useful discussion webinar. However, it would be particularly valuable if international discussions could be organised specifically on how IC/BPS fits into the ICD-11 classification framework, with IC/BPS clinicians and patient advocates involved.

If you would like to read more about ICD-11, go to <https://europeanpainfederation.eu/sip-news/why-do-we-need-to-implement-the-icd-11/>

We were informed that there is likely to be a WHO pain classification webinar on 14 June, 2023. This will be announced with further details by the IASP and EFIC shortly.

REVIEW OF AUA 2023 – 28 APRIL to 1 MAY - CHICAGO

Although urology conferences these days tend to be dominated by urological cancers and men's problems, this year IC/BPS was certainly not forgotten at the American Urological Association (AUA) Annual Meeting and appeared in all shapes and sizes. At the SUFU 2023 Annual Meeting at the AUA, Larissa Rodriguez gave a presentation on New Developments in IC, while the AUA Course 017IC, chaired by Q. Clemens, A. L. Ackerman and H. Lai, looked at Emerging Concepts in Interstitial Cystitis/Bladder Pain Syndrome. Pelvic pain was a topic in a basic sciences symposium on New Developments in Understanding and Treating Pelvic Pain which looked at the latest basic and translational research studies and also the main neural and non-neural signalling pathways and modulatory factors contributing to the pelvic pain and involved in visceral sensation. Neuroscientist Dr Aaron Mickle, presenting on a New

Approach to Study Urothelial Cells and Their Role in Bladder Pain, reported that one of the key gaps in knowledge is the role urothelial cells play in bladder pain.

There was emphasis placed at this year's AUA on the need for phenotyping and subgrouping. What is clearly emerging at last is the realisation that Hunner Lesion patients must be treated and researched as a separate group, while it is now urgently necessary to phenotype the non-lesion patients so as to optimise treatment. However, at the present time this can result in many studies still having too few patients participating and researchers experiencing difficulty in recruiting the right patients for the right study. This is likely to be a challenge for future studies focused on specific phenotypes or sub-groups.

At the Poster and Podium session PD05 on Infections/Inflammation/Cystic Disease of the Genitourinary Tract: interstitial cystitis, chaired by Jeremy Burton, Henry Lai and John Lavelle, there were many interesting abstracts presented, so we can only zoom in on a small selection.

Oluwarotimi Nettey presented a study on *Distinct Phenotypes of Bladder Pain Identified the Multidisciplinary Approach to the Study of Chronic Pelvic Pain Research Network Dataset*, noting that the hallmark of urologic chronic pelvic pain is pain or pressure originating from the bladder, that there is no unifying consensus definition to guide diagnosis and that there are big gaps in our approach. This patient group, she said, is particularly challenging since it is heterogeneous, debilitated and resistant to treatment. Furthermore there are no validated clinical biomarkers and no prognostic indicators to match patients to the different treatments. The study was based on 3 bladder pain phenotypes: myofascial pelvic pain (MFP), bladder-specific pain symptoms (BPS: bladder pain increased with filling, bladder pain relieved by emptying) and non-urologic pelvic pain symptoms (NUPP). They were using machine learning (ML) algorithms and concluded that unsupervised ML algorithms may help delineate phenotypic differences among patients with bladder pain. However, further studies are needed to investigate if ML clustering can predict treatment response.

In the presentation on *Small Fiber Polyneuropathy as a Therapeutic Target for Patients with Interstitial Cystitis/Bladder Pain Syndrome*, Wyatt Whitman noted that patients have a variety of co-occurring urologic and non-urologic symptoms and syndromes and there is a need for therapies tailored to each patient. This study concerned small-fibre polyneuropathy (SFPN), commonly found in patients with fibromyalgia. This group found that SFPN is common in IC/BPS patients while patients with Hunner lesion are significantly less likely. They concluded that for a large subset of IC/BPS patients with a systemic pain disorder, SFPN could prove to be an important new therapeutic target.

In *Bladder-directed versus pelvic floor therapy in women with interstitial cystitis/bladder pain syndrome: preliminary results*, it was good to see that Kenneth Peters described IC as a syndrome including urinary urgency!! Just a few years ago urgency in IC was removed from the symptom list and reserved exclusively for OAB. It is a great relief to know that IC/BPS influencers have now at last returned this distressing symptom back to IC patients!

Curtis Nickel from Canada presented a most interesting study on *Infection phenotype in Interstitial cystitis/bladder pain syndrome : Does bacterial-induced mucosal cellular immune imbalance hypersensitivity explain response to MV140 recurrent UTI vaccine?* This study

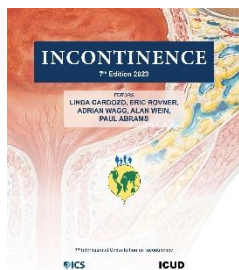
concerned a sublingual MV140 vaccine against rUTI which could potentially help a subgroup of patients with bladder hypersensitivity and IC-like symptoms and with recurrent UTI. There is currently a huge increase in interest in UTIs and especially recurrent UTIs, including in IC/BPS patients, with many conference presentations recently on this topic. So this ongoing study is very welcome.

Elevated FM/a Blood Test in Patients with Interstitial Cystitis / Bladder Pain Syndrome, presented by Claire Burton, basically looked at a potential immune process going on in IC/BPS.

In Serum Anandamide and Lipids Associated with Linoleic Acid Can Distinguish Interstitial Cystitis and Bladder Pain Syndrome from Overactive Bladder, Kazumasa Torimoto from Japan presented a study looking at another hot topic: how to distinguish IC/BPS from overactive bladder as there currently appears to be a confusing overlap. Torimoto noted that a practical biomarker should have the ability to discriminate between diseases that cause increased urinary frequency and especially OAB. In this study, they aimed to search for blood biomarkers that can discriminate between IC/BPS and OAB. They found that serum anandamide may be a good candidate as a diagnostic biomarker for IC/BPS. Low serum anandamide levels might be associated with the initiation of pain and inflammation and may reflect the pathology of IC/BPS.

This was only a brief overview of just a little of the interesting material related to IC/BPS presented at AUA 23. Hopefully we will see some of it published in the coming months.

BOOKS, PUBLICATIONS



INCONTINENCE 7th Edition (2023).

Cardozo, L, Rovner, E, Wagg, A, Wein, A, Abrams, P. (Eds) Incontinence 7th Edition (2023). ICI-ICS. International Continence Society, Bristol UK, ISBN: 978-0-9569607-4-0.

Now available as ebook.

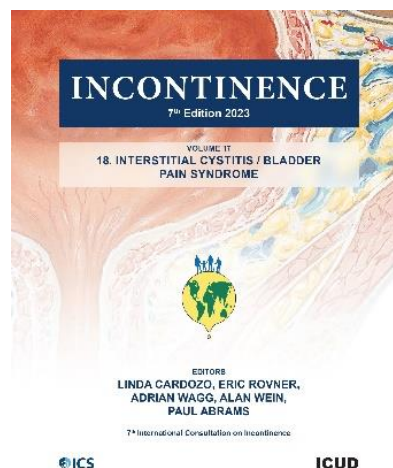
Incontinence 7th Edition (ICI 7) forms a comprehensive reference work covering the entire field of continence for all disciplines in 2023. While it is based on the ICI-ICS consultation held in 2021, publication was delayed by Covid. However, it is now available for purchase from the International Continence Society (ICS). The book is the result of extensive international input from the world's leading experts in the field of continence and is an unrivalled reference text for all clinicians, researchers and students in the field.

For the first time, buyers will be able to buy the entire book in digital format, unlocking the option to order printed copies of the chapters of their choice, making this ideal for all.

The price for the whole book is £200.00 and £70.00 for ICS members. Once you have purchased the eBook, you will have exclusive access to purchase print versions of each of the individual chapters. Further information and ordering: <https://www.ics.org/shop>, www.ics.org/ici

Chapter 18 covers Interstitial Cystitis / Bladder Pain Syndrome

and is therefore of special interest to us and comprises no fewer than 333 pages. The international committee working on this IC/BPS chapter was chaired by Philip Hanno, (United States), and included Mauro Cervigni (Italy), Myung-Soo Choo, (Republic of Korea), J. Quentin Clemens, (United States), Daniela Gold, (Austria), Ming Huei Lee, (Taiwan), Sachin Malde, (United Kingdom), Jane Meijlink, (Netherlands), Michael Samarinas, (Greece), Tomohiro Ueda (Japan). This chapter covers history, recommendations for terminology, patient perspective, epidemiology, etiology, pathology, diagnosis, confusable disorders, classification and phenotyping, conservative treatment, oral treatment, intravesical treatment, botulinum toxin, neuromodulation, surgical therapy, outcome assessment, impact on quality of life, principles of management, major findings from the MAPP research network, future directions in research, algorithms and more besides. A very useful reference work.



StatPearls: <https://www.ncbi.nlm.nih.gov/books/NBK430685/>

- **AMITRIPTYLINE**

Amit Thour, Raman Marwaha.

In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan.

2023 Feb 16. PMID: 30725910 Bookshelf ID: NBK537225

Free Books & Documents

Amitriptyline is FDA approved medication to treat depression in adults. The Non-FDA approved indications are anxiety, post-traumatic stress disorder, insomnia, chronic pain (diabetic neuropathy, fibromyalgia), irritable bowel syndrome, interstitial cystitis (bladder pain syndrome), migraine prophylaxis, postherpetic neuralgia, and sialorrhea. This text reviews the indications, contraindications, activity, adverse events, and other key elements of amitriptyline in the clinical setting related to the essential points needed by members of an interprofessional team managing the care of patients that can benefit from amitriptyline therapy.

- **INTERSTITIAL CYSTITIS**

Yizhe Lim, Seanan O'Rourke.

In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan. 2023 Feb 8.

PMID: 34033350 Bookshelf ID: NBK570588

Free Books & Documents

Interstitial cystitis is a condition that affects the urinary bladder, characterized by chronic inflammation. It is not secondary to an infection. In many cases, because it remains a diagnosis of exclusion, the condition is often diagnosed late in the patient's journey. Patients often describe pain in the bladder region (suprapubic), with a strong sensation to want to urinate (urgency). This sensation is worsened by filling the bladder and is often relieved by passing urine more often (frequency). This may be during the daytime and/or during the night (nocturia). There may also be other symptoms such as pain or discomfort on passing urine (dysuria) and pain or discomfort during sexual intercourse, known as dyspareunia. Due to

these symptoms, there is a profound impact on the emotional, psychological and social well-being of the patient.

- **DYSURIA**

Parth Mehta, Stephen W. Leslie, Anil Kumar Reddy Reddivari. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan.2023 Mar 6. PMID: 31751108 Bookshelf ID: NBK549918

Free Books & Documents

Dysuria is defined as the sensation of pain and/or burning, stinging, or itching of the urethra or urethral meatus associated with urination. It is a very common urinary symptom experienced by most people at least once over their lifetime. Dysuria typically occurs when urine comes in contact with the inflamed or irritated urethral mucosal lining. This is exacerbated by and associated with detrusor muscle contraction and urethral peristalsis, which then stimulates the submucosal pain receptors resulting in pain or a burning sensation during urination. Several conditions can cause dysuria via different mechanisms. True dysuria requires differentiation from other symptoms, which can also occur due to pelvic discomfort from various bladder conditions such as interstitial cystitis, prostatitis, and suprapubic or retropubic pain.

CLINICAL AND EXPERIMENTAL RHEUMATOLOGY JOURNAL SUPPLEMENT ON SJÖGREN'S

The Sjögren's Foundation (<https://sjogrens.org>), based in the USA, recently announced that the journal *Clinical and Experimental Rheumatology* has released its annual supplement on Sjögren's. The aim of this supplement is to update readers on the leading topics in this complex and rapidly growing field by publishing editorials, reviews, and original articles pertinent to Sjögren's. This is particularly useful reading for those with an interest in the IC/BPS autoimmune phenotype.

Co-editors for this year's supplement include: M. Bombardieri (UK), H. Bootsma (The Netherlands), S. De Vita (Italy), T. Dörner (Germany), M. Ramos-Casals (Spain), and A.G. Tzioufas (Greece). Associate editors for the issue were C. Baldini (Italy) and E. Bartoloni (Italy).

Sections of this supplement include: In memoriam; a meeting report from the 15th annual ISSS; One year in review; Editorials; Full papers; Reviews; Letters to the editor; and abstracts from the 15th annual ISSS. The supplement is free to view and accessible online, at:

<https://www.clinexprheumatol.org/a.asp?IDArchivio=268>

WEB INFORMATION

GLOBAL INTERSTITIAL CYSTITIS BLADDER PAIN SYNDROME (GIBS) - INDIA

GIBS India comprises medical caregivers, support staff, patient advocates. Its purpose is to educate the urologist, urogynecologist/gynaecologist, GPs, patients and the general public. Organises regular webinars open to all. <https://gibsociety.com/>

UROLOGY ACADEMY UK WEBSITE ON BPS FOR PROFESSIONALS

This website is a UK-specific educational resource for the management of patients with Bladder Pain Syndrome: <https://urologyacademy.co.uk/>.

OVERVIEW OF UPCOMING EVENTS

ESSIC CONGRESS 2023

6-8 Jul 2023, New York, USA.

Meeting Chair: Robert Moldwin. The meeting will include keynote lectures, debates, panel discussions and more, as well as networking events. Check the ESSIC Congress website to keep updated and to subscribe to the ESSIC 2023 newsletter. Information & updates:

www.essicmeeting.eu

GIBS 2023: 8TH ANNUAL CONGRESS ON INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME

26-27 August 2023, Mumbai, India. Theme: "Compassion & Care for Bladder Flare".

www.gibsociety.com

13th CONGRESS OF THE EUROPEAN PAIN FEDERATION EFIC

20-22 September 2023, Budapest, Hungary

<https://europeanpainfederation.eu/>

53rd ANNUAL MEETING OF THE INTERNATIONAL CONTINENCE SOCIETY (ICS 2023)

27 – 29 September 2023, Toronto, Canada.

This includes a state-of-the-art lecture on "Bladder Pain Syndromes: Have we made any advances in our understanding?" by Dr Michael Chancellor.

<https://www.ics.org/2023>

CONVERGENCES PP ANNUAL MEETING 2023

19-21 October 2023 in Barcelona, Spain.

<https://www.convergencespp.com/en/>

EAU 24

5-8 April 2024 in Paris, France

Venue: Paris Expo Porte de Versailles

<https://eaucongress.uroweb.org/announcing-eau24/>

AUA 2024

3-6 May 2024, San Antonio, USA

<https://www.auanet.org/AUA2024>

20TH WORLD CONGRESS ON PAIN

5-9 August 2024, Amsterdam, Netherlands

IASP's 50th Anniversary!

<https://www.iasp-pain.org>

DONATIONS AND SPONSORING – THE IPBF NEEDS FINANCIAL SUPPORT TO CONTINUE ITS INTERNATIONAL PATIENT ADVOCACY AND AWARENESS CAMPAIGN AROUND THE GLOBE.

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to continue to carry out its international advocacy, projects and newsletters. In these difficult economic times, it is not easy for us to keep going and ensure continuity. All donations to our

international work, however small, will be most gratefully received. The IPBF has fiscal charity status in the Netherlands. If you are thinking of making a donation, please go to this link for bank details: http://www.painful-bladder.org/donations_sponsoring.html

We would like to take this opportunity of thanking our donors for their greatly appreciated support in the past year for our foundation, projects, patient advocacy, website and newsletters.

THE BOARD - INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF)

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