

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2015

FOUNDATION INFORMATION:

IPBF Board:

Chairman: Jane Meijlink

Treasurer: Florentina Ferreyra

Secretary: Toby Meijlink

Member: Nagendra Mishra MD

Member: Dorothy Milne RN

IPBF Medical Advisory Board:

The International Painful Bladder Foundation is grateful to receive support and advice from a voluntary medical advisory board that plays an active role in the foundation. The members of this board are currently as follows:

Belgium:	Jean-Jacques Wyndaele, MD, urologist
Canada :	Jerzy Gajewski, MD urologist
Czech Republic:	Libor Zámecník, MD, urologist
Germany:	Daniela Marschall-Kehrel, MD urologist
India:	Nagendra Mishra, MD, urologist
Mexico:	José Luis Campos Contreras, MD, urologist
Poland:	Piotr Radziszewski, MD, urologist
Portugal:	Paulo Dinis Oliveira, MD, urologist
Russia:	Dimitry Pushkar, MD, urologist Andrey Zaitcev, MD, urologist
Saudi Arabia:	Waleed Altaweel, MD, urologist
South Africa:	Hans-Heinrich Rabe, MD, urologist
Taiwan:	Alex Tong-Long Lin, MD, urologist
United Kingdom:	Christopher Chapple, MD, urologist Paul Irwin, MD, urologist
USA:	Philip Hanno, MD, urologist Robert M Moldwin, MD, urologist Grannum Sant, MD, urologist

The **Stichting International Painful Bladder Foundation** (IPBF) was formally incorporated as an international non-profit voluntary organisation by notarial deed on 2 September 2005 and was registered at the Chamber of Commerce in Rotterdam, the Netherlands under number: 24382693 on 5 September 2005. Its official address is located in Rotterdam. In all legal issues, Dutch law prevails. The Foundation has fiscal charitable status in the Netherlands, Charity Fiscal Number: 8168.41.597.

OBJECTIVES AND MISSION OF THE IPBF:

The International Painful Bladder Foundation is a voluntary non-profit organisation with the objective of raising awareness of IC/BPS and Hunner Lesion worldwide among patients, health professionals and the general public by means of its website, e-newsletter to well over 4500 patients and health professionals worldwide, publications, presentations and congress booths, with the aim of ensuring that IC/BPS patients worldwide get the right diagnosis and treatment. The IPBF helps support groups get started and provides them and existing groups with the latest information on developments. The IPBF stimulates and participates in research, participates in international discussions where it puts forward the viewpoint of the global patients and encourages international cooperation.

The mission of the International Painful Bladder Foundation is:

- To promote the interests of patients with interstitial cystitis/bladder pain syndrome, Hunner Lesion, hypersensitive bladder, chronic pelvic pain and associated disorders;
- To increase awareness and knowledge of interstitial cystitis/bladder pain syndrome, hypersensitive bladder, chronic pelvic pain syndrome and associated disorders among patients, doctors and other healthcare providers, health institutions, industry and the general public worldwide by gathering and disseminating, by any means and in any form, the most up-to-date knowledge and information about these disorders;
- To stimulate international scientific research;
- To promote international cooperation between people involved in interstitial cystitis/bladder pain syndrome, hypersensitive bladder, chronic pelvic pain syndrome and associated disorders;
- To enter into joint ventures in any form and any place with organizations working to promote similar medical or patient interests;
- To raise funds for the purpose of carrying out these activities;

ACTIVITIES IN 2015

Despite some upheaval in the first half of 2015 due to moving house from Rotterdam to Naarden and setting up a new office, the International Painful Bladder Foundation nevertheless played a very active international role in the year 2015. Much of its work involved international consultation, discussion, education including the provision and exchange of information, giving presentations, participations in working groups as well as specific projects within a wide framework.

During 2015, the IPBF's activities included the following:

Awareness and information

In 2015 the IPBF continued to focus much attention on raising awareness of IC/BPS and associated disorders worldwide at all levels (patients, professionals, health authorities, industry) and provided high quality, up-to-date information on the latest insights, developments and research in the field of diagnosis and treatment of IC/BPS, Hunner Lesion and associated disorders through its website, newsletter, publications and presentations and active participation in committees and working groups. There is still a considerable problem concerning terminology and definitions, with several different names being used, leading to reimbursement issues for the patient in specific countries. This was elaborated in an article published in 2015 in *Translational Andrology and Urology*. During 2015, the IPBF website and other information and educational materials were updated. The IPBF website was maintained and continually updated by its webmaster throughout 2015. The information and educational materials on the website are produced in the simplest way possible so as to allow regular updating and easy downloading. The website provides a regularly updated review of the latest scientific publications.

The IPBF e-Newsletter continues to be a success and the IPBF receives many requests from both patients and health providers to be added to the mailing list. The IPBF currently has well over 4500 subscribers to its e-Newsletter. These subscribers come from the patient world, family doctors, medical specialists in different specialisms, continence nurses, pelvic floor physiotherapists and industry, many of whom in turn circulate the newsletter to their networks. The patient support groups often use the information for their own newsletters, particularly research items. In this way the information provided gets circulated to a much wider readership. In 2015, e-Newsletters were produced in January April, August and December.

Capacity building

On request, the IPBF also helps new (local) patient support groups get started, and keeps group leaders updated on the latest (scientific) developments so as to build their capacity, ensure continuity for the future and provide support groups with international information for their own newsletter or other materials. It also endeavours to ensure that support groups are aware of information (books, videos, CDs etc) produced by other patient organisations in the field of IC/BPS and associated disorders. Continuity is a problem, particularly with smaller support groups. In the longer term, the workload involved is often too much for people who are themselves patients and/or are also trying to hold down a regular job at the same time.

Global advocacy

Global patient advocacy is a key aspect of the work of the IPBF. The IPBF presents the viewpoints of the patients and patient organisations and the impact on and consequences for the patient of any changes or developments. Throughout 2015, the IPBF was continually in touch with all parties involved in guidelines, definitions and terminology, with the chairman participating in the ICS standardisation working group on chronic pelvic pain and giving a presentation on the impact of standardisation and changes in terminology and definitions on the patient and the patient's family at the patient session held during the 2nd World Congress on Abdominal and Pelvic Pain held in Nice, France, 11-13 June 2015 and again during the annual ESSIC meeting held in Rome, Italy, 17-19 June 2015, with an abstract also accepted in this field at ESSIC.

The IPBF chair represents the patient point of view in the ICS Standardisation Steering Committee and has done this for 8 years with one more year to go with participation in four standardization working groups. It has proved to be very worthwhile and the IPBF has emphasised that when terminology and definitions are changed, the practical impact on the patient has to be taken into account.

The IPBF coordinates between different stakeholders involved in IC/BPS so as to help to create global cooperation and collaboration, since this is in the interests of the patients. In 2015, this included giving a presentation on IC/BPS at a pharma company's European meeting and pointing out what patients actually want.

Memberships

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO), EURORDIS for rare diseases in Europe, Pain Alliance Europe (PAE), the International Pelvic Pain Partnership (IPPP) and the new International Pain Management Network (IPMN) and plays an active role in these organisations. The IPBF is also associated with the International Continence Society (ICS), the European Association of Urology (EAU) and the International Association for the Study of Pain (IASP).

Research

The IPBF particularly stimulates research into areas where it feels research has been neglected, but that would be in the best interests of the patients. IPBF board members are frequently consulted by research and guideline groups. The IPBF chair participated very actively in four ongoing ICS standardisation projects. The IPBF has also been involved in discussions on Hunner Lesions and on glomerulations, with the IPBF chair co-authoring an article on glomerulations.

Support for patients

The IPBF receives many letters and phone calls from patients in distress around the world. Where necessary, the IPBF medical advisory board is called in to provide further information and we are very grateful for all the help and advice they provided during 2015. In doing this work, we work closely with our colleagues in national support groups to try to find help for these patients. There was again considerable interaction in this respect between support groups during 2015. This has proved to be an excellent way of finding optimal solutions for individual patients with problems.

Special thanks to Sponsors

The IPBF would like to thank its sponsors in 2015: Mylan, Oxyor bv, Grunenthal and several private donors. The IPBF is dependent on donations and the funding received in 2015 allowed the foundation to continue its work, play a role in vital international discussions, distribute information and educational material worldwide and help patients in all parts of the globe. However, it is becoming more and more difficult to find sponsors, particularly as a result of the global economic crisis. This is affecting not only the IPBF but also IC/BPS support groups worldwide.

SPECIFIC PROJECTS, ACTIVITIES AND EVENTS UNDERTAKEN AND ATTENDED BY THE IPBF IN 2015

INTERNATIONAL PAIN MANAGEMENT NETWORK STEERING COMMITTEE MEETING, BERLIN, GERMANY, 6-8 MAY 2015.

The IPBF chair attended a meeting of the steering committee of the new International Pain Management Network in Berlin. The IPBF helped to develop the global patient survey on pain management, distributed in 2015 and 2016.

2nd WORLD CONGRESS ON ABDOMINAL AND PELVIC PAIN, 11-13 JUNE 2015, ACROPOLIS NICE, FRANCE

Following the success of the 1st WCAPP in Amsterdam in 2013, this second multidisciplinary World Congress on Abdominal & Pelvic Pain was organized in Nice, France by Convergences in PelviPerineal Pain (Convergences PP), a federation of different French scientific societies concerned with chronic pelvic perineal pain, in collaboration with the Abdominal and Pelvic Pain (AAP) special interest group (SIG) of the International Association for the Study of Pain (IASP), the International Pelvic Pain Society (IPPS). The International Pelvic Pain Partnership (IPPP), a patient alliance, also participated and organized a parallel patient workshop on one day of the conference, along with many French patient organizations. WCAPP was organized parallel to the meeting of the International Urogynaecological Association (IUGA) with a half-day shared session. The theme of the conference was to endeavour to understand how patients can suffer often extreme levels of pain with no visible abnormalities on the basis of standard tests (clinical, bacteriological, endoscopic imaging) or with minor lesions that are disproportionate to the symptoms and to examine how this pain can be legitimately treated with no available evidence base, in relation to interstitial cystitis/bladder pain syndrome, chronic prostatitis, endometriosis, pelvic congestion, vulvodynia, irritable bowel syndrome, proctalgia fugax, adhesions, chronic pelvic pain, pudendal nerve pain, musculoskeletal dysfunction, low back pain and the issue of central sensitization. Key messages that echoed throughout the conference were: 1. The need for a multidisciplinary approach; 2. Look at the whole patient, holistic approach, while at the same time phenotyping; 3. The need for personalized treatment, as every patient is different; 4. The aim of treatment is to improve quality of life for the patient. The IPBF chair gave a presentation on how and why patients should participate in guidelines and standardisation projects. [Click here.](#)

ANNUAL MEETING OF ESSIC (INTERNATIONAL SOCIETY FOR THE STUDY OF BPS) ROME, ITALY, 17-19 SEPTEMBER 2015

The annual meeting of ESSIC (International Society for the Study of BPS) was held at the Gemelli Hospital Catholic University of Rome with over 200 delegates. It was good to see so many younger healthcare professionals attending. With many experts now around retirement age, it is important to encourage younger doctors to continue the crusade. Patients were not forgotten either, with a patient speaker session forming part of the programme, and a number of patient representatives, particularly from Italy, in the audience. The meeting was divided into themed sessions and each session was followed by a question and answer session. The IPBF chair gave two presentations. A special detailed review of this meeting available on both the IPBF and ESSIC websites. [Click here.](#)

ANNUAL SCIENTIFIC MEETING 2015 INTERNATIONAL CONTINENCE SOCIETY 45th ANNUAL SCIENTIFIC MEETING 6-9 October 2015, Montreal, Canada

In recent years, the International Continence Society (ICS) has increasingly developed a special interest in pelvic dysfunction and pelvic pain, including interstitial cystitis/bladder pain syndrome (IC/BPS) and hypersensitive bladder (HSB) in addition to the field of incontinence. This has made the ICS annual scientific meeting an important date in the conference calendar for those with a focus on IC/BPS. This year's meeting in Montreal was no exception with podium sessions on research, a selection of workshops in the field of pelvic pain and dysfunction, bladder sensation, pudendal neuralgia, a round table discussion on urgency (which rather regrettably focused on overactive bladder urgency only, with painful urgency as in IC/BPS largely forgotten), an update on IC/BPS, vestibulodynia and pelvic pain syndromes in the Pan-Arab Continence Society (PACS) session (stressing multimodal treatment and a multidisciplinary team), while a large part of the final morning was devoted to understanding pelvic pain and – a first for the ICS – a round table discussion and presentations around the topic of bladder pain syndrome/interstitial cystitis: pain and phenotypes. The IPBF chair also attended a meeting of the ICS Standardisation Steering Committee, representing the patient point of view, as well as meetings of standardization working groups on chronic pelvic pain syndromes and nocturia. [Click here.](#)

E-NEWSLETTERS

E-Newsletters were produced in January, April, August and December and distributed worldwide by email. [Click here.](#)

PUBLICATIONS 2015

A special Focused Supplement on Interstitial Cystitis/Bladder Pain Syndrome, Edited Sant/Saban (Open Access) was published in two parts in October and December 2015. The open access means that patients can freely

obtain these articles. Two IPBF board members – Jane Meijlink and Nagendra Mishra, MD - participated in this project:

- Meijlink JM. Patient-centred standardization in interstitial cystitis/bladder pain syndrome—a PLEA. *Transl Androl Urol* 2015. doi: 10.3978/j.issn.2223-4683.2015.08.02
- Mishra NN. Clinical presentation and treatment of bladder pain syndrome/interstitial cystitis (BPS/IC) in India. *Transl Androl Urol*. 2015 Oct;4(5):512-23. doi: 10.3978/j.issn.2223-4683.2015.10.05.

Supplement Part I: Vol 4, No 5 (October 2015). [Read more...](#)

Supplement Part II: Vol 4, No 6 (December 2015). [Read more...](#)

- Wennevik GE, Meijlink JM, Hanno P, Nordling J. The role of glomerulations in Bladder Pain Syndrome - A review. *J Urol*. 2015 Aug 26. pii: S0022-5347(15)04683-2. doi: 10.1016/j.juro.2015.06.112. [Epub ahead of print]
- Meijlink JM, van Kerrebroeck P. Interstitial Cystitis: from Enigma to International Consensus? Chapter 28. In: *Milestones in Urology*. Felderhof E, Mattelaer J, Moll F, Schultheiss D, Van Kerrebroeck P (Eds). EAU History Office and Davidsfond Uitgeverij NV. 2015
This history book was produced to mark the 30th annual congress of the European Association of Urology.

2015 A SUCCESSFUL AND ACTIVE YEAR

2015 was again a successful and extremely active year for the IPBF. IPBF board members in different parts of the world have raised awareness at all levels, set up local projects and provided many patients with practical information and emotional support.

The chairman would like to thank all IPBF board members for their hard work, help, advice and input during the year 2015 and to thank all IC support groups for their feedback and cooperation. Thanks are also due to our webmaster Joop P. van de Merwe, MD, for maintaining the IPBF website throughout the year.

INCOME AND EXPENDITURE 2015 SUMMARY

Sponsor funding and donations received:	€ 12,563.54
General operating expenses:	€ 4,368.00
Information material, CDs, website, project expenses:	€ 7,603.05

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 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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