

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2017

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 address is located in Naarden. 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 Hypersensitive Bladder, Interstitial Cystitis, Bladder Pain Syndrome and Hunner Lesion worldwide among patients, health professionals and the general public by means of its website, e-newsletter to over 4500 patients and health professionals worldwide, publications, presentations and congress booths, with the aim of ensuring that IC/BPS/HSB 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 and panels 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 hypersensitive bladder, interstitial cystitis, bladder pain syndrome, Hunner Lesion, chronic pelvic pain syndromes and associated disorders;

- To increase awareness and knowledge of hypersensitive bladder, interstitial cystitis, bladder pain syndrome, Hunner lesion, 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 and participate in international scientific research;
- To promote international cooperation between people involved in interstitial cystitis/bladder pain syndrome, hypersensitive bladder, chronic pelvic pain syndromes 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 2017

During the year 2017, the International Painful Bladder Foundation continued to play a very active international role. Much of its work involved international consultations with patients, doctors and industry, discussions, teleconferences, education including the provision and exchange of information, giving presentations at workshops, meetings and congresses, participation in European and international working groups, in a European research consortium, as well as specific standardisation projects.

IPBF is regularly consulted by Pharma or University research groups developing drugs and seeking grass roots information about this bladder disease.

Meetings and conferences attended

The IPBF attended a number of meetings and conferences during 2017. During March, when the IPBF representative was unable to attend in person due to illness, videos were made and shown at the European Patient Summit and the annual congress of the EAU. In March a brainstorming meeting was held in London organized by HIVE on behalf of Mylan. In June the IPBF chair attended a meeting of the ICS Standardisation Steering Committee and also in the same month the Societal Impact of Pain (SIP) conference held in Malta where a pre-conference meeting was held for IC/BPS patient representatives. The IPBF chair gave presentations at an educational workshop at the annual meeting of the International Continence Society in Florence and at the annual meeting of ESSIC in Budapest. A Planning Meeting for a potential new European Chronic Urogenital Pain Alliance was also attended in Amsterdam in November. Furthermore, many meetings were held during the year in the form of teleconferences. During 2017, board member Nagendra Mishra organised and attended a number of meetings on IC in India with the aim of increasing awareness and knowledge, while Dorothy Milne continued her extensive work programme throughout New Zealand where they have a very flourishing group and newsletter.

Awareness and information

In 2017, the IPBF continued to focus attention on raising awareness of IC/BPS/HSB and associated disorders worldwide at all levels (patients, professionals, health authorities, pharma 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/HSB, Hunner Lesion, chronic pelvic pain syndromes and associated disorders through its website, eNewsletter, publications and presentations and active participation in committees and working groups.

During 2017, the IPBF website and other information and educational materials were updated. The IPBF website was maintained and continually updated by its webmaster throughout 2017. 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 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 4000 subscribers to its eNewsletter. These subscribers come from the patient world, family doctors, medical specialists in different specialisms, continence nurses, pelvic floor physiotherapists and pharma 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. E-Newsletters were produced in January, May and October and distributed worldwide by email.

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Capacity building

On request, the IPBF also helps new (local) patient support groups get started. In 2017, Jane Meijlink and Dr Nagendra Mishra continued to help an Indian patient to set up web information for Indian patients and provided her with information that could be adapted to suit the Indian situation. The IPBF keeps patient organisations updated on the latest (scientific) developments which they can adapt to use in their own newsletters. It also endeavours to ensure that support groups are aware of information (books, videos, CDs, web material, blogs, etc) produced by other patient organisations in the field of IC/BPS/HSB and associated disorders.

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 2017, the IPBF was continually in touch with all parties involved in guidelines, definitions and terminology, with the chairman representing patients as a member of the ICS standardisation steering committee and participating in working groups on chronic pelvic pain syndromes, conservative management, nocturia and lower urinary tract dysfunction.

European Advocacy

The IPBF participated throughout 2017 in a multi-organisation planning group working towards potentially setting up a European alliance for chronic urogenital and pelvic pain.

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 International Pain Management Network (IPMN) steering committee 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, including by giving presentations at conferences and workshops and through direct contact with medical professionals. IPBF board members are frequently consulted by research and guideline groups. The IPBF chair participated very actively in ICS standardisation projects. The IPBF has been consulted by several pharma companies about the patient perspective in relation to development of new drugs for IC/BPS/HSB and to provide advice and information from the grass roots.

The IPBF is also represented in the European IMI Pain Care Research Consortium which includes urogenital pain.

Publications in 2017 with IPBF participation

JOURNAL ARTICLES

- Meijlink JM. Bladder pain: the patient perspective. *Urologia*. 2017 Sep 14;84(Suppl 1):5-7. doi: 10.5301/uj.5000261. Epub 2017 Aug 17. Review.
- Bo K, Frawley HC, Haylen BT, Abramov Y, Almeida FG, Berghmans B, Bortolini M, Dumoulin C, Gomes M, McClurg D, Meijlink J, Shelly E, Trabuco E, Walker C, Wells A. An International Urogynecological Association (IUGA)/International Continence Society (ICS) joint report on the terminology for the conservative and nonpharmacological management of female pelvic floor dysfunction. *Neurourol Urodyn*. 2017 Feb;36(2):221-244. doi: 10.1002/nau.23107.
- Deggweiler R, Whitmore KE, Meijlink JM, Drake MJ, Frawley H, Nordling J, Hanno P, Fraser MO, Homma Y, Garrido G, Gomes MJ, Elneil S, van de Merwe JP, Lin AT, Tomoe H. A standard for terminology in chronic pelvic pain syndromes: A report from the chronic pelvic pain working group of the international continence society. *Neurourol Urodyn*. 2017 Apr;36(4):984-1008. doi: 10.1002/nau.23072.

BOOKS

- Meijlink JM, Moldwin RM. The Evolution of Therapy for Chronic Pelvic Pain. Chapter 1. In: *Urological and gynaecological chronic pelvic pain*. Moldwin RM (Ed.). Springer 2017. Pages 1-14.
- Meijlink JM. The Changing Role of Organized Patient Support for the Chronic Pelvic Pain Patient. Chapter 2. In: *Urological and gynaecological chronic pelvic pain*. Moldwin RM (Ed.). Springer 2017. Pages 15-24.

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 2017.

Problem areas

There is still a considerable problem concerning terminology and definitions, with several different names being used, leading to devastating reimbursement issues for patients in many countries. Many patients are unable to have the treatment they need.

The IC/BPS/HSB world is facing the problem of many of its top experts retiring and too few urologists interested in specialising in this field. There are also still too few who have the expertise to diagnose Hunner lesions with certainty. The large urology associations are showing less and less interest in the field of chronic urogenital pain and particularly IC/BPS/HSB. As a result, trainees are focusing their attention in other fields.

Special thanks to Sponsors

The IPBF would like to thank its sponsors in 2017: Mylan, Oxyor bv, Grunenthal, IBSA and private donors. The IPBF is dependent on donations and the funding received in 2017 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.

2017 A SUCCESSFUL AND ACTIVE YEAR

2017 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 2017 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 and to all members of our Medical Advisory Board.

INCOME AND EXPENDITURE 2017 SUMMARY

Sponsor funding and donations received:	€ 13,453.85
General operating expenses:	€ 4,442.39
Information material, IT/website, project and congress expenses:	€ 5,737.76
Carried Forward (€ 3,273.70)	

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.

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

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