

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2019

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 Zámečník, 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 2019

2019 was a particularly busy year from January to December. During 2019, the International Painful Bladder Foundation once again played an active international role including presentations at workshops, meetings and congresses, participation in European and international working groups, for example in the European IMI-PainCare research consortium (TRiPP project), as well as starting on two international guideline projects.

In 2019, the IPBF chair was part of the local organizing committee for the ESSIC annual scientific meeting in Amsterdam, 5-7 December 2019 where a special effort was made to involve far more patient advocates than before.

The IPBF is regularly consulted by medical researchers around the world as well as patients and their organisations. The IPBF provided help and advice to many different support groups in 2019 on request with the additional aim of passing on knowledge and expertise gained over the years so as to help educate the upcoming generation of patient advocates.

MEETINGS AND CONFERENCES ATTENDED

Research Meetings

The IPBF is an official participant in the European IMI-PainCare Research Consortium which includes the TRiPP project with its emphasis on research into endometriosis and IC/BPS. 2019 was again a year of intensive work, with the IMI-PainCare General Assembly held in Berlin 19/20 March and monthly teleconferences throughout the year.

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 has been consulted by several pharma companies about the patient perspective in relation to development of new treatments for IC/BPS/HSB and to provide advice and information from the grass roots. The IPBF is also consulted by Cochrane.

Conferences and Presentations

The IPBF attended the World Congress on Abdominal & Pelvic Pain (WCAPP) 11/12 May 2019 in London, United Kingdom. This conference discussed the latest research and developments in abdominal and pelvic pain fields and focused on pain from a life-course and lifestyle approach. A review of this conference was written for the IPBF website and newsletter.

The annual scientific meeting of the International Continence Society (ICS) attended by the IPBF is an important date in the IPBF calendar and was held 3-6 September 2019, Gothenburg, Sweden. IPBF chair Jane Meijlink gave a workshop presentation on the patient perspective. This society recently established the "ICS Institute", which comprises "Schools" to serve the e-learning needs of members and provide training in designated centres of excellence. One of these is a School of Pelvic Pain which also includes IC/BPS. The IPBF chair is a member of this committee. A review of this meeting was written for the IPBF website.

ESSIC is the International Society (originally the European Society) for the Study of Bladder Pain Syndrome/Interstitial Cystitis and its associated disorders. The ESSIC annual scientific meeting was held in Amsterdam, 5-7 December 2019. The IPBF chair was a member of the local organising committee and also gave two presentations, one on Associated Disorders and an abstract on the need to reinstate sensory urgency in the definition of IC/BPS. A further presentation was given during the networking meeting for IC/BPS support group advocates and other interested parties organised by the Dutch IC Patient Association (ICP) at the end of the ESSIC conference. An extensive review of this meeting was written for the IPBF website.

Other Activities

Much communication and discussion today takes place through teleconferences and webinars and 2019 was no exception with multiple teleconferences throughout the year.

Publications

IPBF chair was co-author of a revision of ICS terminology on Nocturia published in 2019.

(Hashim H, Blanker MH, Drake MJ, Djurhuus JC, Meijlink J, Morris V, Petros P, Wen JG, Wein A. International Continence Society (ICS) report on the terminology for nocturia and nocturnal lower urinary tract function. Neurourol Urodyn. 2019 Feb;38(2):499-508. doi: 10.1002/nau.23917. Epub 2019 Jan 15. PMID: 30644584.)

A further paper was also published in 2019 along with invited editorial comment for the International Journal of Urology supplement on the ICICJ conference in Kyoto in 2018.

(Meijlink J. Interstitial cystitis/bladder pain syndrome/hypersensitive bladder: Worldwide confusion! What has gone wrong and how can we put it right for the sake of the patients? Int J Urol. 2019 Jun;26 Suppl 1:41-45. doi: 10.1111/iju.13973.)

Awareness and information

In 2019, 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, e-Newsletter, publications and presentations and active participation in committees and working groups.

During 2019, the IPBF website and other information and educational materials were updated. The IPBF website was updated by its webmaster throughout 2019. The information and educational materials on the website are produced in the simplest way possible so as to allow easy updating and downloading.

The IPBF e-Newsletter and Research Update 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 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 February, May, August and November 2019 and distributed worldwide by email. [Click here.](#)

Capacity building

On request, the IPBF also helps new (local) patient support groups get started. In 2019, IPBF Board members continued to help new support groups. 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. Furthermore, the IPBF is doing everything possible to pass on as much information as possible to the younger generation of patient advocates. We have noticed a change in the type of support group, which has at least in part moved from the traditional group to online social media contact. It is still extremely difficult to find volunteers willing to take on any tasks to help keep a support group going.

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.

Memberships

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO), EURORDIS for rare diseases in Europe and Pain Alliance Europe (PAE). 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).

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 2019.

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 essential treatment they need because they simply cannot afford it. This is also partly due to lack of scientific evidence due to inadequately designed studies and failure to phenotype/subtype.

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. An Atlas is needed but never seems to get off the ground. The ESSIC conference made a big endeavour to attract younger urologists to the meeting.

Special thanks to Sponsors and Donors

The IPBF would like to thank its sponsors and donors in 2019. The IPBF is dependent on donations. Funding received in 2019 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.

2019 A Successful and Active Year

2019 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 2019 and to thank all IC support groups for their feedback and cooperation. Many thanks are also due to our webmaster Joop P. van de Merwe, MD, for maintaining the IPBF website throughout the year, to all members of our Medical Advisory Board and many other health professionals who have been very generous with their help and advice.

INCOME AND EXPENDITURE 2019 SUMMARY

Sponsor funding and donations received:	€ 11,865.13
General operating expenses:	€ 4,897.36
Information material, IT/website, project and congress expenses:	€ 6,475.38
Carried Forward (€ 492.39)	

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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