

## ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2018

### 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 2018**

During 2018, 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, in the European IMI-PainCare research consortium (TRiPP project), as well as projects related to the standardisation of terminology and definitions. The IPBF is regularly consulted by medical researchers and industry around the world as well as patients and their organisations.

### **MEETINGS AND CONFERENCES ATTENDED**

#### **Patient Meetings**

A number of European meetings for patient representatives and patient organisations for diseases in the field of chronic pelvic and urogenital pain were held again in Amsterdam in 2018, sponsored by industry. A patient summit was held in March with many excellent presentations given by patient advocates, followed by a further European meeting in June. This allowed good contacts to be made between European patient groups and was an ideal opportunity to reflect on the overlaps between different chronic pelvic and urogenital diseases and disorders. ICA-Germany and the IPBF helped with the organisation of these events.

#### **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. After working intensively in the pre-start-up period, the IPBF attended the kick-off general assembly meeting in Aachen, Germany. This was followed by a TRiPP project meeting at the Medical Research Council Harwell Campus in Oxfordshire, UK and regular monthly teleconferences.

#### **Conferences**

The IPBF was represented at the annual congress of the European Association of Urology in March. Of particular interest was the session on the European e-Urogen. The 4th ICICJ (International Consultation on Interstitial Cystitis Japan) was a major event in our field in April 2018 and was attended by the IPBF chair who also gave a presentation which is to be included in a special supplement of the International Journal of Urology in 2019. Special pre-conference workshops were organised to discuss controversial topics and areas where changes are needed. In August, the IPBF was present at the annual scientific meeting of the International Continence Society where the IPBF chair gave a workshop presentation. 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. At the end of November, the IPBF attended the ESSIC annual meeting. ESSIC is the International Society (originally the European Society) for the Study of Bladder Pain Syndrome/Interstitial Cystitis and its associated disorders. The IPBF chair gave two presentations, one of which emphasized the problems for patients due to non-reimbursement of treatment. While this is a global problem, it is particularly bad in Europe.

#### **Other Activities**

Much communication and discussion today takes place through teleconferences and webinars and 2018 was no exception with multiple teleconferences throughout the year.

#### **Publications**

IPBF chair Jane Meijlink continued working in 2018 on revision of ICS terminology on Nocturia which has now been published. "Bladder Pain Syndrome – An Evolution" was published in 2018 with chapter 2 by the IPBF chair. Further information: <http://www.springer.com/gp/book/9783319614489>.

### **Awareness and information**

In 2018, 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 2018, the IPBF website and other information and educational materials were updated. The IPBF website was maintained and continually updated by its webmaster throughout 2018. 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 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 4000 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 January, June and October and distributed worldwide by email. [Click here.](#)

### **Capacity building**

On request, the IPBF also helps new (local) patient support groups get started. In 2018, 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.

### **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).

### **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 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.

### **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 2018.

### **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 and private donors in 2018. The IPBF is dependent on donations and the funding received in 2018 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.

### **2018 A Successful and Active Year**

2018 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 2018 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 2018 SUMMARY**

Sponsor funding and donations received:	€ 13,074.33
General operating expenses:	€ 4,494.58
Information material, IT/website, project and congress expenses:	€ 10,338.45
Carried Forward (€ 1,758.70)	

*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.*

© 2019 International Painful Bladder Foundation