

## ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2013

### 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.

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO), EURORDIS for rare diseases in Europe, Pain Alliance Europe and the International Pelvic Pain Partnership and plays an active role in these organisations. The IPBF is also associated with the Continence Promotion Committee of the International Continence Society (ICS).

**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 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 2013**

The International Painful Bladder Foundation once again played an active international role in the year 2013. Much of its work involved international consultation, discussion, education including the provision and exchange of information, giving presentations, as well as specific projects.

During 2013, the IPBF's activities included the following:

**Awareness and information**

In 2013 the IPBF continued to focus a great deal of attention on raising awareness of IC/BPS and associated disorders worldwide and provided high quality, up-to-date information on the latest developments in the field of diagnosis and treatment of IC/BPS, Hunner Lesion and associated disorders through its website, newsletter, congress booths, publications and presentations. While many more patients are now being diagnosed worldwide, there are still countries where IC/BPS is unknown and where IC/BPS is not a registered disorder. There is also a major problem concerning terminology and definitions, with several different names being used, leading to reimbursement issues for the patient.

During 2013, the IPBF website and other information and educational materials were updated. The CD Rom was once again a success. The IPBF brochure was again fully updated. This brochure was again highly popular in 2013.

The IPBF website was maintained and continually updated by its webmaster throughout 2013. 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. The IPBF currently has well over 4500 subscribers to its e-Newsletter. These subscribers come from the patient world, medical specialists in different specialisms, continence nurses and increasingly pelvic floor physiotherapists, many of whom in turn circulate the newsletter to their networks. The patient support groups often use the information for their own newsletters. In this way the information gets circulated to a much wider readership. In 2013 the IPBF once again received many requests from patient support groups to use particularly research items from the IPBF e-Newsletter in their own newsletter. In 2013 e-Newsletters were produced in February, June and October. The IPBF continually receives requests both by email and via the IPBF congress booths from people around the world wishing to be added to the newsletter mailing list.

### **Capacity building**

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.

### **Global advocacy**

Global patient advocacy plays a key role in 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. Throughout 2013, 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 history of terminology and definitions in Kyoto 2013. The IPBF chair represents the patient point of view in the ICS Standardisation Steering Committee and has done this for several years. 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.

### **Memberships**

In 2013 the IPBF once again played an active role in the umbrella organisations EURORDIS, IAPO, Pain Alliance Europe (PAE) and the International Pelvic Pain Partnership (IPPP) and as an associate of the International Continence Society (ICS).

### **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 two ongoing ICS standardisation projects and was invited to speak on the topic of standardisation at the international meeting in Kyoto – ICICJ3/ESSIC – in March. The IPBF has also been involved in discussions on Hunner Lesions and 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 2013. In doing this work, we work closely with our colleagues in national support groups to try to find help for these patients.

### **Special thanks to Sponsors**

The IPBF would like to thank its sponsors in 2013: Mylan, Uroplasty and Oxyor bv and private donors. The IPBF is dependent on donations and the funding received in 2013 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 2013**

#### **Royal Society of Medicine event on Urogenital Pain, 18 January 2013 at the Royal Society of Medicine, Wimpole Street, London, UK.**

This was an excellent event on Urogenital Pain organised by the Royal Society of Medicine. In addition to state-of-the-art presentations, there was also plenty of time for discussion and questions. [Click here](#) for a review of the meeting.

#### **ICS Publication and Communications Committee Meeting, 9 February 2013, London, UK**

The IPBF represents the IC/BPS patient world in the widest sense in the International Continence Society, including some 8 years on this committee.

#### **Joint Meeting of the 3rd International Consultation on Interstitial Cystitis Japan (ICICJ3) and the ESSIC Annual Meeting 2013, 21-23 March 2013, Mielparque, Kyoto, Japan**

The dedicated meeting was the highlight of the year for the IC/BPS world at which latest developments, scientific insights and international viewpoints were presented and discussed. The IPBF chair was invited to give the introductory presentation on the topic of interstitial cystitis – a history of nomenclature, definitions and criteria, spanning two centuries, emphasising that in today's electronic world it is no longer a simple matter to change terminology and that account needs to be taken of the impact on the patient in practical terms, such as reimbursement of treatment. The IPBF speaker was then invited to write a paper on her presentation topic for a special supplement of the International Journal of Urology to be published in March 2014.

[Click here](#) for a detailed review of the meeting.

#### **American Urological Association Annual Meeting 2013, 4-8 May 2013, San Diego, USA**

This major urological event was an ideal opportunity to update our knowledge by attending all courses on IC/BPS and all aspects of chronic pelvic pain. It was also an important moment to meet with colleague organisations and to hold discussions on controversial issues with doctors in the field. [Click here](#) for a review of this meeting.

#### **1<sup>st</sup> World Congress on Abdominal & Pelvic Pain, 30 May-1 June 2013, Beurs van Berlage, Amsterdam, Netherlands**

This conference was an entirely new and exciting initiative at which abdominal and pelvic pain was examined from every possible angle. The IPBF also participated in a special multidisciplinary workshop organised by the International Pelvic Pain Partnership and following the meeting shared in the writing of a chapter for a book to be produced by the congress organisers. The IPBF also shared a stand for patient information. [Click here](#) for a review of this event.

#### **International Continence Society Annual Scientific Meeting 2013, 25-31 August 2013, Barcelona, Spain**

This is always a particularly active meeting for the IPBF and two board members attended. The ICS had kindly given us a complimentary booth at which we distributed a huge amount of information. We created a special poster for our booth for this occasion, with the kind assistance of Professor Andrey Zaitcev from Moscow, to raise awareness of Hunner Lesion. We also attended scientific

presentations, workshops, committee meetings, standardisation working group meetings and participated in international discussions. [Click here](#) for a review of this meeting.

**European Association of Urology (EAU) - European Parliament Urology Round Table Meeting  
“How to Provide the Right Prevention and Treatment to the Right Patient at the Right Time”.  
25 September 2013, Brussels, Belgium**

The IPBF was invited by the EAU to attend this international urology round table meeting at the European Parliament in Brussels, co-organised by the European Alliance for Personalised Medicine (EAPM) and the European Association of Urology (EAU) and hosted by Petru Lohan, Romanian MEP and active health campaigner. More than a dozen speakers addressed the broader issues of personalised medicine in terms of urology (although mainly from the viewpoint of urologic cancer). Reviewed in [October 2013 Newsletter](#).

**NEWSLETTERS**

Newsletters were produced in February, June and October 2013 and distributed worldwide by email. [Click here](#).

**BOOK CHAPTER**

The IPBF contributed towards a book chapter produced by the International Pelvic Pain Partnership as part of the book to be published in 2014 by IASP on the 1<sup>st</sup> World Congress on Abdominal & Pelvic Pain.

**WEBSITE**

In addition to updating the large brochure on IC/BPS and other information, the IPBF also produced a first (pilot) fact sheet on **Ketamine Abuse and the Urinary Tract**, aimed at raising awareness of the serious IC/BPS and Hunner lesion-like symptoms caused by the very concerning, rapidly increasing use of street ketamine among young people. [Click here](#).

**2013 A SUCCESSFUL AND ACTIVE YEAR**

2013 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 2013 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**

Sponsor funding received:	€ 10,969.24	
General operating expenses:		€ 3,457.07
Information material, CDs, website, project expenses:		€ 9,488.39

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