

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2014

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 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 2014

The International Painful Bladder Foundation played an active international role in the year 2014. Much of its work involved international consultation, discussion, education including the provision and exchange of information, giving presentations, as well as specific projects within a wide framework.

During 2014, the IPBF's activities included the following:

Awareness and information

In 2014 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 developments and research in the field of diagnosis and treatment of IC/BPS, Hunner Lesion and associated disorders through its website, newsletter, congress booths, publications and presentations. 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 issue was referred to in a presentation on Standardisation at the ICS annual scientific meeting. During 2014, the IPBF website and other information and educational materials were updated. The CD Rom was once again a success. The popular IPBF brochure was again fully updated in 2014 and distributed for example at the IAPO and ESSIC meetings. The IPBF website was maintained and continually updated by its webmaster throughout 2014. 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, 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 gets circulated to a much wider readership. In 2014 e-Newsletters were produced in January, May and September. The IPBF continually receives requests both by email from people around the world requesting to be added to the newsletter mailing list.

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.

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 or

developments. Throughout 2014, 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 ICS 2014 annual scientific meeting in Rio de Janeiro. 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

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 Network for Understanding Pain (INUP) and plays an active role in these organisations. The IPBF is also associated with 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 annual scientific meeting of the ICS in a special workshop organised by the ICS Standardisation Steering Committee in October. 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 2014. In doing this work, we work closely with our colleagues in national support groups to try to find help for these patients. There was considerable interaction in this respect between support groups during 2014. This has proved to be an excellent way of finding optimal solutions for individual patients with problems. Where necessary, we call on members of the Medical Advisory Board to help out.

Special thanks to Sponsors

The IPBF would like to thank its sponsors in 2014: Mylan, Oxyor bv and several private donors, including medical professionals. The IPBF is dependent on donations and the funding received in 2014 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 2014

IAPO 6TH GLOBAL PATIENTS CONGRESS

The International Alliance of Patients' Organization's (IAPO) 6th Global Patients Congress, held in Ascot, United Kingdom 29-31 March 2014, was attended by some 178 delegates from no fewer than 48 countries worldwide! These included many patient advocates from all parts of the world attending this congress for the first time who were welcomed at a special breakfast briefing on the Saturday when it was emphasised that a strong point of IAPO is that it has always welcomed patient organisations on all scales, large and small, and everyone's voice counts. Furthermore, one organisation faced with a problem can learn from others who may have found a solution. The theme of the Congress explored: 'Better access, better health: A patient-centred approach to universal health coverage'. Delegates explored the role of the patient in defining and implementing universal health coverage globally. A wide range of stakeholders, including patients, policy-makers, healthcare professionals, academics and industry representatives discussed the challenges in achieving healthcare for all. Patient representatives emphasised that no system is truly universal if it is not providing equitable, high quality, affordable access to healthcare. These are the three pillars of universal health coverage. To improve access to

healthcare for all, patients need to be involved in the design and delivery of healthcare. For this, patients need a strong, unified voice. Delegates agreed that patients are increasingly working together, and with other stakeholders, to achieve access to healthcare for all. However, there was a plea for training of patient leaders in all aspects of healthcare so as to ensure that they can effectively participate in the system on behalf of their members, a plea strongly endorsed by all of us.

The congress was an ideal opportunity for networking and for meetings of same interest groups, including the **International Pelvic Pain Partnership** (<https://www.facebook.com/pages/International-Pelvic-Pain-Partnership/229848217207564>), organised by Judy Birch from the UK and attended by several patient representatives from the IC/BPS world, and a first meeting of those interested in the proposed setting up of a new **International Network for Understanding Pain (INUP)**, organised by Penney Cowan from the USA, which likewise proved to be of great interest to IC/BPS representatives.

ESSIC ANNUAL MEETING 13-15 JUNE, PHILADELPHIA, USA

The 2014 ESSIC annual meeting was a unique occasion because it was the first ESSIC (International Society for the Study of Bladder Pain Syndrome) annual meeting to be held in the United States. Meeting hosts Philip Hanno, MD, Kristene Whitmore, MD, and Jørgen Nordling, MD emphasised that the focus of the meeting would be on the differences between patients with and without Hunner lesion, with the aim of making it an interactive meeting with maximum discussion. Jane Meijlink (IPBF) gave a presentation on Guy Hunner and his work. Attendees from around the world included patient advocates Lee Claassen (ICA Executive Director, USA), Rhonda Garrett (ICA, USA), Vicki Ratner, MD (Founder and President Emeritus ICA, USA), Loredana Nasta (President AICI, Italy) and Jane Meijlink (Chair IPBF, Netherlands), all of whom played an active role in this meeting. There was a detailed update on the NIH/NIDDK MAPP project (Multidisciplinary Approach to the study of chronic Pelvic Pain) presented by Chris Mullins, PhD, from the NIDDK, followed by J. Quentin Clemens, MD (from University of Michigan Medical Center) who is chair of the MAPP Network. The working groups on the second day, focusing on different themes related to Hunner lesion, also included a patient advocates working group. It is hoped that all working group findings will be included in an article for publication.

INTERNATIONAL CONTINENCE SOCIETY (ICS) ANNUAL SCIENTIFIC MEETING, RIO DE JANEIRO, BRAZIL, 20-24 October 2014

This year's annual scientific meeting of the International Continence Society (ICS) was held in Rio de Janeiro, Brazil. In recent years, those involved in IC/BPS and chronic pelvic pain have been aware that less and less space is being devoted to this in many of the urology and urogynaecology conferences. However, the ICS is an exception and at this year's meeting a number of workshops were presented in this field, as well as dedicated podium sessions and many posters. Since the ICS multidisciplinary field of activity covers pelvic floor dysfunction in a wide sense, including bowel/rectal dysfunction as well as the urinary tract, along with neurological aspects, and is seen from medical, physiotherapy, nursing and patient advocate points of view, it provides a more comprehensive picture of dysfunction and pain in the pelvic floor. A great deal of research into IC/BPS and hypersensitive bladder is being done in East Asia, including Japan, Taiwan, South Korea and China, as can be seen from the research presented at this meeting. Taiwan is also an important centre for research into ketamine cystitis. There is still some confusion in studies presented regarding what type of patient they are referring to: whether it concerns Hunner lesions or non-lesion IC/BPS. Some studies refer only to "refractory IC patients" without giving further details, while a number still have patients diagnosed on the basis of the old NIDDK criteria. The latter is particularly the case in retrospective studies. This makes comparison of studies confusing if not impossible. IPBF Chair Jane Meijlink was invited to speak on behalf of the patients at a special standardisation steering committee workshop on setting the standards; developing new ICS standards in the era of evidence-based medicine. The "Standards" are one of the key initiatives of the ICS. The ICS Standardisation Steering Committee has modernised the approach to developing ICS standards, using the principles of evidence-based medicine. The new approach has been designed to develop relevant practical and up-to date standards in a concise manner. What was completely new here was having a patient advocate (Jane Meijlink) to speak on the impact of new or changed terminology and definitions on the patient and why it is important to involve patients in the whole process of developing terminology and definitions. Standardization has an impact on every link in the healthcare chain, directly affecting the patient with regard to diagnosis, treatment, eligibility for reimbursement, social benefits and care. Official recognition of a condition is vital, so coding must be correct and uniform across all authorities. Particularly important for the patient is that official recognition of the condition means eligibility to receive: reimbursement of treatment, unemployment benefits, disability benefits and a whole range of social services and care. Patients should be involved in the standardization process to ensure that all aspects of a condition are covered and no patients or symptoms are

excluded. Patient organizations can provide standardization professionals with supplementary information, helping to create a comprehensive picture of each condition and everything this involves along the healthcare chain.

PAIN ALLIANCE EUROPE AND SOCIETAL IMPACT OF PAIN (SIP) 2014, 17-18 NOVEMBER, 2014, BRUSSELS

The well-attended Pain Alliance Europe (PAE) members' General Assembly took place at Thon Hotel in Brussels on Monday, November 17, 2014. Patient representatives came from a wide variety of organizations with pain implications from all over Europe. They called for urgent concrete action to prioritize chronic pain at an EU level, to increase public awareness of chronic pain and its visibility, to educate health professionals at all levels and to stimulate research and data collection. It was felt that many proposals have been put forward but no concrete action has been taken at an EU level and this needs to change. It was also felt that there needs to be more sharing of information and cooperation between patient organizations and more cooperation between patient organizations and professionals in order to further their goals. This meeting was followed by a useful networking dinner together with delegates to the SIP Symposium. The following day, the 5th Societal Impact of Pain (SIP) Symposium was held at the SQUARE Brussels Meeting Centre, having been switched from the original venue at the European Parliament due to the large number of attendees. There were around 200 delegates, twice the number of the previous year. SIP is an international platform set up in 2010 that provides opportunities for discussion for health care professionals, pain advocacy groups, politicians, insurances, representatives of health authorities, regulators and budget holders. This meeting gives everyone a chance to share thoughts, opinions, plan effective actions and meet key people. This year, the SIP conference had an entirely new (experimental) panel format involving all stakeholders and moderated by the well-known Nick Ross who pointed out that analgesics were first used thousands of years ago. So why are huge numbers of people still suffering huge amounts of pain, he asked? 100 million people in the EU suffer from this and 500 million sick days are lost. The cost is therefore multi billions, with massive utilization of health resources.

Panel discussion topics included:

- Out of sight, out of mind – why the reluctance to see pain as a critical issue?
- Good practice – how do we stimulate innovation and accelerate the replication?
- Outcome of the Italian Presidency's discussion on Pain and Palliative Care at the informal Ministerial Council. What now?
- The future – how can stakeholders advocating for the recognition of pain in Europe work together to ensure change?
- There was also an interview with three patient advocates: making the invisible visible – the experience of living with chronic pain.

NEWSLETTERS

Newsletters were produced in January, May and September and distributed worldwide by email.

[Click here.](#)

PUBLICATIONS

Interstitial cystitis and the painful bladder: A brief history of nomenclature, definitions and criteria.

Jane M Meijlink.

A Special Issue of the International Journal of Urology with free access to all articles was published in April 2014. This formed a review of the 3rd International Consultation on Interstitial Cystitis Japan (ICICJ) and International Society for the Study of Bladder Pain Syndrome (ESSIC) Joint Meeting, 21–23 March 2013, Kyoto, Japan. This included an article by IPBF Chair Jane Meijlink on Interstitial cystitis and the painful bladder: A brief history of nomenclature, definitions and criteria.

2014 A SUCCESSFUL AND ACTIVE YEAR

2014 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 2014 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 and donations received:	€ 12,500.00
General operating expenses:	€ 4,176.28
Information material, CDs, website, project expenses:	€ 9,634.95

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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