

Annual Report of the Stichting International Painful Bladder Foundation (IPBF) for the year 2012

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 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 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 and the Pain Alliance Europe 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/PBS worldwide among patients, health professionals and the general public by means of its website visited by over 80 countries, e-newsletter to well over 4000 patients and health professionals worldwide, publications, presentations and congress booths, with the aim of ensuring that IC/PBS 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 painful bladder syndrome, interstitial cystitis, chronic pelvic pain and associated disorders;
- To increase awareness and knowledge of painful bladder syndrome, interstitial cystitis, 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 painful bladder syndrome, interstitial cystitis, 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 2012

The International Painful Bladder Foundation once again played an active international role in the year 2012. Much of its work involved international consultation, discussion, education including the provision and exchange of information, giving presentations, as well as specific projects.

During 2012, the IPBF's activities included the following:

Awareness and information

In 2012 the IPBF continued to focus a great deal of attention on raising awareness of IC/PBS 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/PBS 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/PBS is unknown and where IC/PBS is not a registered disorder.

During 2012, 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 2012. During 2012 the IPBF also included information leaflets from many different IC support groups and related patient associations and websites on congress booths.

The IPBF website was maintained and continually updated by its webmaster throughout 2012. 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 2012 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 2012 e-Newsletters were produced in January, April, July 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 IC patient organisations.

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 2012, 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 the international discussion group on harmonisation of definitions and terminology organised by the ESSIC in Rome, 2012. The IPBF coordinates between different stakeholders involved in IC/PBS so as to help to create global cooperation and collaboration, since this is in the interests of the patients.

Memberships

In 2012 the IPBF once again played an active role in the umbrella organisations Eurordis and IAPO. It became a member of the Pain Alliance Europe (PAE) which is a relatively new European patient umbrella organisation, launched at the European Parliament on 29 November 2012, which was set up to improve the quality of life of people living with chronic pain in Europe and with the aim of promoting awareness of chronic pain, promoting European policy on chronic pain and reducing the impact of chronic pain on European society. It aims to achieve this by working closely with all other stakeholders, by gathering and distributing information on chronic pain from the patient point of view and by promoting or initiating research into chronic pain. It also is a member of the International Pelvic Pain Partnership. In addition, the IPBF worked actively in 2012 as an associate of the Continence Promotion Committee of the International Continence Society (ICS), attending its committee meetings and the "ICS Meets Continence Societies" working lunch held in Beijing at the annual scientific meeting.

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 groups. In 2012 we were again invited to review guidelines. The IPBF chair participated in two ongoing ICS standardisation projects and was invited to participate in the international discussions on definitions organised by ESSIC in Rome. The chair was also invited to participate in a European research group making a bid for EU funding for research into bladder pain.

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 2012. In doing this work, we work closely with our colleagues in national support groups to try and find help for these patients.

Thanks to Sponsors

The IPBF would like to thank its sponsors in 2012: Bioniche Pharma Group Ltd, Oxyor bv and private donors. The IPBF is dependent on donations and the funding received in 2012 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 finding sponsors, particularly as a result of the global economic crisis. This is affecting not only the IPBF but also IC support groups worldwide.

SPECIFIC PROJECTS AND ACTIVITIES UNDERTAKEN BY THE IPBF IN 2012

27TH ANNUAL CONGRESS OF THE EUROPEAN ASSOCIATION OF UROLOGY (EAU),

Paris, France, 24-28 February 2012.

The Annual Congress of the European Association of Urology (EAU) was held at the Palais des Congrès de Paris, 24-28 February 2012 and opened with the 5th International Consultation on Incontinence (ICI), with Committee 19 presenting on Bladder Pain Syndrome. A review of the research presented at the EAU congress related to IC/BPS was placed on the IPBF website.

IAPO 2012

The IPBF was one of the many organisations represented at the 5th Global Patients Congress held by the International Alliance of Patients' Organizations (IAPO) in London 17-19 March 2012. The Congress brought together the most important voices in healthcare, those of the patients, with other healthcare stakeholders on an equal footing. Delegates from over 30 countries working across diseases and across borders came together to enable engagement and understanding of key policy issues affecting patients in the international arena. The 5th Global Patients Congress examined how we measure the extent to which patient-centred healthcare is achieved around the world. It not only highlighted examples of best practice but also examined how meaningful indicators can be developed to measure patient involvement within healthcare systems.

CHRONIC PELVIC PAIN PATIENT MEETING HELD IN LONDON ON 17 MARCH

During the IAPO meeting, a workshop hosted by the Pelvic Pain Support Network, CEO Judy Birch, was held on Saturday 17 March in the afternoon and was attended by patient representatives from pelvic pain, vulvar pain and bladder organisations from the UK and other parts of Europe, including the IPBF. This workshop was focused on working together to make the treatment of chronic pelvic and perineal pain more effective and patient-centred. The objectives were to discuss and understand perspectives and experiences of chronic pelvic pain – across different organisations; to discuss and agree the root causes and effects if ineffective care and treatment; to agree some priority areas on which participating organisations can work together and to agree on some next steps.

CONVERGENCES PP 2012

26-28 April, Nîmes, France

Convergences PP is a federative meeting on pelviperineal pain with expert speakers in this field from around the world. A number of patient advocates representing different organisations from Europe in the field of pelvic pain also attended, including many IC patient support groups, and a patient workshop was held on the role of patient associations.

ESSIC ANNUAL MEETING 2012

Porto, Portugal, 10-12 May 2012.

The focus of this year's meeting was "pain" which was particularly appropriate since Portugal was in fact the first country to hold a National Pain Day in 1999. Another area of attention was the issue of international harmonisation of terminology and definitions for which plenty of time was allowed for discussion. The meeting also included a patient session comprising presentations by two patient advocates. IPBF chair Jane Meijlink gave a presentation on pain from a patient perspective.

3RD SOCIETAL IMPACT OF PAIN SYMPOSIUM (SIP 2012)

Copenhagen, Denmark, 29-31 May 2012

Over four hundred people from more than 30 countries attended the SIP 2012, 3rd Societal Impact of Pain Symposium at the ultra-modern, twin tower Bella Sky hotel and conference centre in Copenhagen, 29-31 May 2012. It was a truly multi-stakeholder meeting, with doctors from many disciplines dealing with chronic pain patients, health authorities, European Parliament, EU Commission DG Sanco, pharmaceutical industry and last but certainly not least representatives from many patient organisations focused on pain or diseases and conditions causing chronic pain, all with the aim of raising awareness on the societal impact of pain, exchanging national best practices and fostering European and national pain care policy projects. The Societal Impact of Pain (SIP) is an international, multi-stakeholder platform created in 2010 provides opportunities for discussion for healthcare professionals, pain advocacy groups, politicians, insurance companies, representatives of health authorities, regulators and budget holders. The new Pain Alliance Europe took advantage of the opportunity to hold a general assembly of its members immediately prior to the start of the symposium in Denmark.

1st SENSORY BLADDER MEETING

Les Pensières, Fondation Merieux, Veyrier du Lac, France, 22-23 June 2012

Around 95 expert speakers and participants from 13 different countries gathered to discuss many different aspects of the "Sensory Bladder" during a multidisciplinary meeting organised by Professors G. Amarenco and E. Chartier-Kastler. The meeting with 25 speakers focused on sensory disorders and the urinary bladder, from anatomy to therapeutic strategies, including the latest information on imaging of the brain and generated a huge amount of information.

14TH WORLD CONGRESS ON PAIN – PUGO Meeting

Milan, Italy. 27-31 August 2012

The World Congress on Pain (WCP), organised every two years by the International Association for the Study of Pain (IASP), is devoted to pain research and treatment. The 2012 congress in Milan was attended by over 7500 delegates from 110 different countries, with all stakeholders represented at this international, multidisciplinary and multicultural congress. On the Sunday prior to the start of the congress, satellite symposiums were organised by the IASP special interest groups or SIGs, including the symposium on "Taking Care of the Patient with Chronic Pelvic Pain", organised by the Pain of UroGenital Origin (PUGO) special interest group and attended by the IPBF. Many patients suffer from chronic pelvic pain – including bladder pain, vulvodynia, irritable bowel syndrome, endometriosis etc – and many different disciplines are involved in caring for these patients. This satellite symposium underlined the fact that a multidisciplinary approach is needed.

INTERNATIONAL CONTINENCE SOCIETY 42nd ANNUAL SCIENTIFIC MEETING

Beijing (China), 15-19 October 2012

A review of the International Continence Society annual scientific meeting was written for the IPBF website. The IPBF, represented by Jane Meijlink, attended the "ICS Meets Continence Societies" working lunch. The IPBF was also represented by Jane Meijlink at the meeting of the ICS Continence Promotion Committee meeting and a presentation on the patient perspective was given at a workshop.

BLADDER PAIN SYNDROME/INTERSTITIAL CYSTITIS: A NEW INSIGHT INTO A PUZZLE.

International Meeting in Rome, 17 November 2012.

The discussion days of this meeting formed the basis for the joint ICICJ 3 and ESSIC annual meeting to be held in Kyoto 2013. Organized by ESSIC, the International Society for the Study of Bladder Pain Syndrome (www.essic.org), the purpose of this meeting was to compare views and insights into nomenclature, definitions, research and therapies. The IPBF chair was invited to participate in the discussions and took every opportunity to present the patient point of view. This was followed by a one-day symposium with the IPBF chair presenting on the patient perspective.

BOOK CHAPTERS

The IPBF chairman was invited to contribute a chapter on diagnosis and treatment of interstitial cystitis to a book on Incontinence being produced in China in Chinese and this was published in 2012. The chairman also contributed a chapter on the Patient Perspective to the ESSIC book Bladder Pain Syndrome, published end 2012.

2012 a successful and active year

2012 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 2012 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:	€ 10,500.00	
General operating expenses:		€ 1,537.31
Information material, CDs, website, project expenses:		€ 8,962.69

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.