

Annual Report of the International Painful Bladder Foundation (IPBF) for the year 2011

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.

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) and EURORDIS for rare diseases in Europe and plays an active role in both of 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 2011

Despite the global economic crisis, the International Painful Bladder Foundation once again played an active international role in the year 2011. Much of its work involved international consultation, discussion, education including the provision and exchange of information, giving presentations, as well as specific projects.

During 2011, the IPBF's activities included the following:

Awareness and information

In 2011 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 2011, the IPBF website and other information and educational materials were updated. The CD Rom was once again a great success and the IPBF distributed numerous copies at its congress booth at the ICS annual conference in Glasgow. The IPBF brochure was once again fully updated. This brochure was again highly popular in 2011. During 2011 the IPBF also included information leaflets from many different IC support groups and related patient associations and websites on its congress booth.

The IPBF website was maintained and continually updated by its webmaster throughout 2011. 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 4000 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 2011 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 2011 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.

E-Newsletters for 2011 can be accessed on the website:

[January 2011](#)

[April 2011](#)

[July 2011](#)

[October 2011](#)

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 an important 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 2011, 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. 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.

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 to mark the occasion of the 2012 annual scientific meeting of the International Continence Society in Beijing.

Memberships

In 2011 the IPBF once again played an active role in the umbrella organisations Eurordis and IAPO. In addition, the IPBF worked actively in 2011 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 Glasgow 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. A hypothesis on drug intolerance and

hypersensitivity in IC patients was presented on two occasions by the IPBF in 2011 and has happily now been taken up by a Canadian research group and mentioned in the report on the ICI-RS presentations on BPS in 2011. IPBF board members are frequently consulted by research groups. In 2011 we were again invited to review guidelines.

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 2011. This concerned patients, both male and female, often in desperate situations, from many different countries. 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 2011: Bioniche Pharma Group Ltd, Oxyor bv and private donors. The IPBF is dependent on donations and the funding received in 2011 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 UNDERTAKEN BY THE IPBF IN 2011

1. AMERICAN UROLOGICAL ASSOCIATION (AUA) ANNUAL MEETING 14-19 MAY 2011, WASHINGTON, USA

A review of the scientific highlights of this meeting was written for the IPBF website. [Click here.](#)

2. INTERNATIONAL CONTINENCE SOCIETY 41TH ANNUAL SCIENTIFIC MEETING 29 AUGUST-2 SEPTEMBER, 2011, GLASGOW, SCOTLAND

- A Review of the International Continence Society annual scientific meeting was written for the IPBF website. [Click here.](#)
- 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
- A booth for IPBF information was organised at the ICS meeting

3. NIH/NIDDK MOMUS meeting

Review of NIH/NIDDK Meeting On Measurement of Urinary Symptoms (MOMUS)

National Institutes of Health, Bethesda, USA, November 14-15 2011, attended by the IPBF chair. [Click here.](#)

4. PRESENTATIONS

A presentation on drug intolerance and hypersensitivity in IC patients with suggestions for research was submitted to the ESSIC meeting held in Moscow, Russia, 2-4 June 2011 and presented at the ICI-RS 2011 meeting in Bristol by Professor P. Hanno on behalf of the IPBF chair.

5. BOOK CHAPTER

A book chapter on diagnosis and treatment of interstitial cystitis was written for the Chinese Continence Society book on Incontinence to be published in 2012, at the request of Professor Limin Liao of Beijing.

6. NEW IPBF TOILET CARDS

Toilet cards were produced in Swedish and Malay at the request of patients and health professionals.

2011 a successful and active year

2011 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 2011 and to thank all IC support groups for their feedback and cooperation. Board member Nagendra Mishra MD continues his extensive work for IC patients in India and handles all requests for help received by the IPBF from Indian patients. Florentina Ferreyra has succeeded in gaining extensive media exposure in Mexico which is having a spin-off effect on Latin America. The IPBF would also like to thank her for her work as treasurer. Dot Milne has continued to rally her IC troops in Christchurch New Zealand and keep the support group running despite continuing earthquakes. Toby Meijlink worked hard throughout the year on IPBF administration and ran the very successful IPBF booth at the ICS annual meeting in Glasgow. Thanks are also due to our webmaster Joop P. van de Merwe, MD, for maintaining the IPBF website throughout the year.

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.