

Annual Report of the International Painful Bladder Foundation (IPBF) for the year 2006

Foundation information:

IPBF Board:

Chairman: Jane Meijlink

Treasurer: Florentina Ferreyra

Secretary: Toby Meijlink

Member: Nagendra Mishra MD

Member: Dorothy Milne RN

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. Application was made to the Dutch tax authority for fiscal charity status and this was granted. As of 1 January 2006, the International Painful Bladder Foundation was officially launched and took over the activities of the International IC Patient Network Foundation which was closed down on the same date.

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO) and EURORDIS for rare diseases in Europe.

Objectives and mission of the IPBF:

The International Painful Bladder Foundation is a voluntary non-profit organisation with the objective of raising awareness of PBS/IC worldwide among patients, health professionals and the general public by means of its website visited by over 80 countries, e-newsletter to almost 4000 patients and health professionals worldwide, publications, presentations and congress booths, with the aim of ensuring that PBS/IC 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 and encourages international cooperation.

The mission of the IPBF is as follows:

- ❖ 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 organisations working to promote similar medical or patient interests;
- ❖ To raise funds for the purpose of carrying out these activities.

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
Czech Republic:	Libor Zámecník, MD, urologist
Germany:	Daniela Marschall-Kehrel, MD
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

Projects undertaken by the IPBF in 2006

The IPBF played an active role in the field of PBS/IC throughout 2006. Much of its work involves continual international consultation, discussion and exchange of information. During 2006 its activities included the following:

Belgian Interstitial Cystitis Patient Association (ICPB) conference 18 February 2006, Vilvoorde, Belgium.

Although this was the second patient conference to be held in Belgium for PBS/IC patients, it was the first official conference and annual general meeting of the new patient support group Interstitiële Cystitis Patiëntenvereniging België. On 18 February in Vilvoorde, the acting chairman of the Belgian support group, Josee de Raa, and her committee were formally confirmed by the members. Jane Meijlink (chairman IPBF) was invited to attend the meeting and participate as speaker together with Professor J-J Wyndaele from Antwerp and to join the new committee for dinner afterwards. The IPBF organised a small info table at this meeting which was greatly appreciated.

IAPO (International Alliance of Patients' Organizations) 2nd Global Patients' Conference

22-24 February 2006, Barcelona, Spain

The IPBF is an associate member of IAPO and plays an active role in this association. IAPO also gives us background information and support in areas where we ourselves have little or no experience such as health politics, patient safety and patient-centred healthcare..

On behalf of the IPBF, Jane Meijlink (chairman IPBF), who was a member of the IAPO conference organising committee, attended the IAPO conference and AGM held in Barcelona. This conference gave the IPBF the opportunity for excellent networking and to build a good relationship with IAPO staff members, other patient organisations and healthcare representatives. New insights were gained into aspects such as patient safety and patient-centred healthcare.

European Association of Urology annual congress
5-8 April 2006, Paris, France

The IPBF had a booth at this congress, distributed a large amount of information including CD Roms for the first time. Many new people were added to our newsletter mailing list. Once again the toilet “Can’t wait” cards in different languages were a huge success and many doctors and nurses took them for their patients. Three board members were present at this conference, Jane Meijlink, Toby Meijlink and Florentina Ferreyra. Scientific presentations on PBS/IC were attended and the information processed in the website and newsletter and patient material.

9th International Symposium on Sjogren’s syndrome
27-29 April, Washington, DC, USA

A group of patients have IC in association with Sjogren’s syndrome. More research into this association might shed light onto the etiology of IC. However, the Sjogren’s experts have largely been ignoring the bladder. This symposium was an opportunity for the IPBF to draw attention to this fact and to remind them that the urinary tract does not stop at the kidneys. This was successful and an SS centre is currently starting a study. Our report on this symposium was translated and used by many patient support groups around the world.

American Urological Association annual conference
20-25 May, Atlanta, USA

Two IPBF board members, Nagendra Mishra MD and Jane Meijlink, attended this conference as Press. Much new research on PBS/IC is always presented at this conference and it is an occasion to interview speakers and collect the latest information on research into PBS/IC for the IPBF website and newsletter. This was successful and the information we gathered was also used by other support groups.

Annual European Congress of Rheumatology (EULAR)
21-24 June 2006, Amsterdam, Netherlands

Jane Meijlink, chairman of the IPBF, attended one day of the EULAR conference with a symposium on Sjogren’s syndrome and took the opportunity to ask the panel questions on IC. This led to some discussion and Professor Moutsopoulos ended the symposium by advising the younger doctors not to forget that SS may also be associated with painful bladder symptoms and that these should be investigated.

NIDDK International scientific symposium on Frontiers in Painful Bladder Syndrome and Interstitial Cystitis, 26-27 October 2006, Bethesda, USA

The IPBF was a co-sponsor of this symposium and undertook international publicity. Two IPBF board members attended, Jane Meijlink and Florentina Ferreyra. This scientific symposium with presentations on the latest research developments led to an emotional debate following the presentation by the European Society for the Study of IC/PBS

of their consensus to change the name to bladder pain syndrome and to omit urgency from the definition. The IPBF stressed the interests of the patients.

The abstract of the patient survey carried out by us at the end of 2005/beginning 2006 on definitions and nomenclature was accepted for a poster presentation at this scientific symposium and attracted plenty of interest. It also helped to lead to a change in attitude to the definition of 'urgency'.

As a co-sponsor, the IPBF was allowed to make a closing speech in which the IPBF chairman, Jane Meijlink, made a plea for international cooperation and consultation. Our support for the patient interests received a great deal of publicity.

Our review of this important symposium was used by support groups everywhere for their websites or newsletters.

International Continence Society annual conference **27 November – 1 December 2006, Christchurch New Zealand**

The ICS organising committee kindly gave the IPBF a complimentary booth in an excellent location with a lot of traffic. The IPBF shared the info booth with the IC support group of New Zealand chaired by Dot Milne. Many doctors, nurses and physiotherapists signed up for the IPBF newsletter and NZ ICSG newsletter. Many excellent contacts were made by all. A huge amount of information was distributed and we were constantly running to the copier! The conference was preceded by a 2-day patient conference superbly organised by Dot Milne at which the IPBF chairman also spoke, including on the NIDDK symposium. The IPBF chairman also gave a presentation on the Patient Perspective at the ICS workshop on PBS/IC.

Website

A completely new website was set up for the new foundation. This is a website with a simple design but is nevertheless a very large website containing a huge amount of information. It is being visited by over 80 countries. It is clear that the patient support groups are making a lot of use of the website as a source of information for their own members.

Newsletter

In 2006 the IPBF e-newsletters were sent in the months January, March, June, August and November to around 4000 people on our emailing list. After every newsletter and every conference attended by the IPBF we receive many requests to be added to the emailing list. The newsletter appears to fill a great need for an overview of international events and developments and provides people with a better overall international picture. Support groups around the world regularly ask for permission to use text from the IPBF newsletter for their own newsletter.

Information Material

In 2006 the IPBF produced a CD Rom for distribution at conferences and proved to be a great success. It can be distributed from a booth or placed on a general info table at a symposium. At the beginning of the year 2006, all material was updated or rewritten. This is a very difficult task bearing in mind all the confusion, changes and developments currently taking place in the IC world. Like all other patient organizations, we are holding our breath regarding the proposed change of name since this would necessitate a further gigantic amount of work.

Participation in Research

The IPBF has a close relationship with the doctors and researchers, and particularly its medical advisory board members, with much interaction. In 2006 the IPBF was very involved in discussions on new definitions, diagnostic procedures and nomenclature. Our plea in the past few years for the term urgency to be redefined is at last being listened to. We carried out a patient survey into the definition of IC, the name and urgency in IC patients.

Patient contact

The IPBF receives many letters and phone calls from patients in distress. With the help of members of our advisory board, we try to provide them with advice or put them in contact with a doctor or support group in their region.

2006 a success

2006 was a successful year for the new foundation. The newsletter is proving a great success and the websites reports on conferences and symposia are being gratefully used by patient support groups around the world. The IPBF also provides health professionals with up-to-date information on diagnosis and treatment. The IPBF is proving to be a stable and neutral focal point in a difficult area of health. During 2006, it worked hard to protect the interests of patients with PBS/IC around the world and will continue to do so in 2007.