

# Annual Report of the International Painful Bladder Foundation (IPBF) for the year 2008

## 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.

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.

### 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 2008

The International Painful Bladder Foundation was exceedingly active during the year 2008.

Much of its work involved international consultation, discussion, the provision and exchange of information as well as specific projects. During 2008, the IPBF's activities included the following:

## Awareness and information

In 2008 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 2008, the IPBF website and other information and educational materials were further developed and updated.

A leaflet in Arabic was developed for the IPBF booth at the International Conference Society conference in Cairo and was subsequently installed on the website. A new short 4 page brochure placed on the website was adjusted several times to keep up with developments and feedback and the brochure on diagnosis and treatment was thoroughly revised. A fact sheet for Primary Care was launched and will be adjusted as we receive feedback. The CD Rom was once again a hit in 2008 and the IPBF distributed around 1500 copies at its congress booths and all other meetings where any kind of info table was available.

During 2008 the IPBF included information leaflets from many different IC support groups and related patients associations on its congress booths.

The IPBF website was maintained and continually updated by its webmaster throughout 2008. 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 over 4000 subscribers to its e-newsletter. These subscribers in turn circulate the newsletter to their networks. The patient support groups use the information for their own newsletters. In this way the information gets circulated to a much wider readership. In 2008 four newsletters were produced in March, June, August and November. The IPBF continually receives requests from people around the world wishing to be added to the newsletter mailing list both by email and via the IPBF congress booths.

Newsletters for 2008 can be accessed on the website:

March 2008:

[http://www.painful-bladder.org/pdf/2008\\_03\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2008_03_Newsletter.pdf)

June 2008:

[http://www.painful-bladder.org/pdf/2008\\_06\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2008_06_Newsletter.pdf)

August 2008:

[http://www.painful-bladder.org/pdf/2008\\_08\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2008_08_Newsletter.pdf)

November 2008:

[http://www.painful-bladder.org/pdf/2008\\_11\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2008_11_Newsletter.pdf)

### 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. The IPBF is also fully aware that materials need adapting to local cultures and situation, and emphasises that leaflets should not simply be translated into the local language but also into the local culture. An important aim is to ensure continuity and the next generation of support group leaders in the IC world.

In 2008, the IPBF worked closely with health professionals who wish to help the patients in their country to eventually set up a support group. It is always very difficult to find IC patients who are willing to take this step. And while IC/PBS patients are often very reluctant to take on responsibility for setting up or helping to run a support group, in many cultures it is additionally actively discouraged and frowned on by the patient's family. This means that other ways have to be sought. Many doctors are now playing a role in helping their local or national patients by providing translated information and/or a web page. With our help, several groups of doctors have set up websites and compiled leaflets in their own language to help patients take this step. Many more informal local support groups have now been set up for patients at hospitals and clinics where accommodation is provided for them to meet.

### Global advocacy

Global patient advocacy plays an important role in the work of the IPBF. At a time when researchers are trying to arrive at new terminology, definitions, criteria and clinical guidelines, the IPBF has been putting forward the viewpoints of the patients and patient organisations and the impact on and consequences for the patient of changes. Throughout 2008, the IPBF endeavoured to ensure that any new definitions accurately reflect the disease as experienced by the patient. This included speaking on behalf of the patients at the SUFU definitions meeting held in Miami. There is still much to be done in this field.

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 2008 the IPBF played an active role in the umbrella organisations Eurordis and IAPO thereby raising the profile of IC/PBS in Europe and worldwide (Eurordis), and learning more about patient-centred healthcare and patient safety (IAPO) in relation to our disease area and passing this information on to patient organisations. The IPBF was also represented on

the organising committee of the IAPO 3<sup>rd</sup> Global Patients Congress. In addition, the IPBF worked actively in 2008 as an associate of the Continence Promotion Committee 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 groups.

#### 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 2008. This concerned patients, often in desperate situations, from many different countries.

#### Thanks to Sponsors

The IPBF would like to thank its sponsors in 2008: the Medtronic Foundation, Bioniche Pharma, Oxyor bv and private donors. The IPBF is dependent on donations and the funding received in 2008 allowed the foundation to play a role in vital international discussions, distribute information and educational material worldwide and help patients in all parts of the globe.

### Projects undertaken by the IPBF in 2008

#### 1. International Alliance of Patients Organizations (IAPO)

Annual Conference + Annual General Meeting

20-22 February, Budapest, Hungary

The IPBF is an associate member of IAPO and was represented on the organizing committee for this conference. Over 180 delegates took part, representing patients and other stakeholders in health such as the European Commission, the World Health Organization, global health professionals' associations and the pharmaceutical industry with the aim of learning from each other's experiences in developing patient-centred healthcare. Another important topic was patient safety. A report was written for the IPBF website and newsletter. ([http://www.painful-bladder.org/pdf/2008\\_IAPO\\_Budapest.pdf](http://www.painful-bladder.org/pdf/2008_IAPO_Budapest.pdf)).

#### 2. IC/BPS/PBS Definition meeting (sponsored by the Society for Urodynamics and Female Urology - SUFU)

27 February, 2008 Miami Florida

This was an invitational international expert meeting on definitions to which the IPBF chairman Jane Meijlink was invited to participate and give a presentation on patient perceptions of urgency and frequency in IC on

behalf of IC patients and to participate in discussions and conclusions. This was followed by attendance at the SUFU conference which immediately followed the Definition Meeting. The IPBF chairman's viewpoint was included in a review article of the meeting by Philip Hanno MD and Roger Dmochowski MD published in 2009 in *Neurourology & Urodynamics*.

### 3. European Association of Urology (EAU)

Annual congress, 26-29 March, Milan, Italy

The IPBF organized a booth at this congress and participated in the scientific programme. There was once again enormous interest in the information we were distributing. Several hundred people signed up for our newsletter. It was also an important opportunity to gain feedback from clinicians about their problems with diagnosis and treatment. A number of doctors consulted us about setting up a patient group or website for their IC patients. A report on the scientific presentations in the field of IC and chronic pelvic pain was written for the IPBF website and newsletter. ([http://www.painful-bladder.org/pdf/2008\\_EAU\\_Milan.pdf](http://www.painful-bladder.org/pdf/2008_EAU_Milan.pdf)).

During this congress, the IPBF arranged a meeting with two members of the EAU Chronic Pelvic Pain Guidelines Committee to discuss definitions, taxonomy and nomenclature from the patient viewpoint. The IPBF invited 2 other patient representatives who were in Milan for the EAU congress to attend this discussion meeting.

### 4. 2<sup>nd</sup> International Consultation on Interstitial Cystitis Japan (ICICJ)

23-25 March, Kyoto, Japan.

This 2<sup>nd</sup> ICICJ symposium and international consultation was attended by IPBF board member Nagendra Mishra MD on behalf of the IPBF. A report was written for the website. ([http://www.painful-bladder.org/pdf/2007\\_ICICJ\\_Kyoto\\_NM.pdf](http://www.painful-bladder.org/pdf/2007_ICICJ_Kyoto_NM.pdf)).

### 5. American Urological Association (AUA) Annual conference

17-22 May, Orlando, USA

With the NIH/NIDDK about to launch its innovative 5-year NIH/NIDDK Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) research programme, every attention was focused at this AUA meeting on IC/PBS/PPP. A full report was written about the scientific research presentations and latest developments for the website and newsletter. ([http://www.painful-bladder.org/pdf/2008\\_AUA\\_Orlando.pdf](http://www.painful-bladder.org/pdf/2008_AUA_Orlando.pdf))

### 6. European Society for the Study of IC/PBS (ESSIC)

5-7 June, Rome, Italy.

Part of the annual meeting of ESSIC was opened to the public and included a course on diagnosis and treatment of IC by IC experts and presentation of the latest scientific research by ESSIC members.

## 7. NIH/NIDDK final consultation meeting on definitions

16-17 June 2008, Bethesda, USA

The international symposium, "Defining the Urologic Chronic Pelvic Pain Syndromes - A new beginning", was organized by the National Institute of Diabetes and Kidney Diseases (NIDDK). In the past two decades, much research has been carried out into interstitial cystitis and chronic prostatitis but has so far failed to lead to any real understanding of the pathophysiology and – most importantly for the patients – has failed to achieve any breakthrough in the field of treatment, let alone cure. It was felt by the NIH/NIDDK that a new approach was necessary. Report on the IPBF website:

[http://www.painful-bladder.org/pdf/2008\\_NIDDK\\_Bethesda.pdf](http://www.painful-bladder.org/pdf/2008_NIDDK_Bethesda.pdf)

## 8. International Consultation on Incontinence (ICI)

(including international committee presenting findings on PBS/IC)  
5-8 July 2008, Paris France.

The IPBF had an information stand at this important scientific meeting and also participated, particularly in the presentation by Committee 19 on Painful Bladder Syndrome, putting forward the patient viewpoint. The IPBF stand was ideally located and the amount of interest in IPBF information and educational material was so enormous that we had to have more printed during the meeting. We were left with the feeling that if there is such a huge need for information on IC/PBS and associated disorders by health professionals, there must be something lacking in basic and ongoing medical education in this field. Report on the IPBF website:

[http://www.painful-bladder.org/pdf/2008\\_ICI\\_%20Paris.pdf](http://www.painful-bladder.org/pdf/2008_ICI_%20Paris.pdf).

## 9. International Association for the Study of Pain (IASP)/PUGO

2-day workshop meeting on urogenital pain and pain taxonomy  
17-22 August, Glasgow, Scotland

This workshop was a satellite meeting of the IASP annual meeting and by the IASP special interest group on pain of urogenital origin. Attended by a broad spectrum of specialists from the pain world (neurologists, pain consultants, anaesthesiologists, neurosurgeons, urologists, gynaecologists, internists, physiotherapists and psychologists) and also by patient representatives including the IPBF chairman, the purpose of this most interesting meeting was to consider the past, present and future of urogenital pain, to outline current practice and to take a look at what the future may hold. Much attention was paid here to interstitial cystitis, chronic prostatitis, endometriosis, pudendal neuralgia and other associated pelvic pain disorders. This proved to be a unique opportunity to view pelvic pain from all possible angles. Each session was followed by interesting, fruitful and certainly very lively interactive discussions, with the patient representatives actively participating and putting the patient point of view. A detailed report was written for the IPBF website and newsletter. ([http://www.painful-bladder.org/pdf/2008\\_PUGO\\_Glasgow.pdf](http://www.painful-bladder.org/pdf/2008_PUGO_Glasgow.pdf))

10. Innovation Forum (drug research and development in Europe)  
29-30 September 2008, London UK

Registration for attendance at this meeting by the IPBF chairman was sponsored by IAPO. It is important for patient representatives to attend these meetings on drug research and development and European regulations, but it demands extensive background knowledge of healthcare policy that the average patient advocate does not have. The IPBF feels that experts from international or European patient umbrella organizations need to attend and then condense the information gleaned from these conferences into something the patient organizations can understand.

11. International Continence Society (ICS)  
Annual conference, 20-24 October, Cairo, Egypt

This was a unique opportunity for the IPBF to raise awareness in this part of the world and the IPBF took advantage of this by organising an information booth at this multi-disciplinary meeting. It was a great success and the nurses, physiotherapists and doctors from the region said how grateful they were. A leaflet in Arabic was compiled and placed on the IPBF website for patients. Hopefully many more patients will now get diagnosed in that part of the world.

During the ICS annual meeting, the ICS Continence Promotion Committee once again organised a Public Forum for the general public in Cairo which this year included a presentation by the IPBF on interstitial cystitis/painful bladder syndrome. First contacts were made with patients in Egypt and the region in this period surrounding the ICS conference. A detailed report was written for the IPBF website and newsletter.

([http://www.painful-bladder.org/pdf/2008\\_ICS\\_Cairo.pdf](http://www.painful-bladder.org/pdf/2008_ICS_Cairo.pdf)).

#### 2008 a successful and very active year

2008 was 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.

Congratulations are due to IPBF board member Nagendra Mishra MD who set up the first IC patient centre in India and the first website for Indian patients in 2008.

The chairman would like to thank all IPBF board members for their hard work, help, advice and input during the year 2008 and to thank all IC support groups for their feedback and cooperation.