

# Annual Report of the International Painful Bladder Foundation (IPBF) for the year 2007

## 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.

## **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 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 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 where it represents 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 2007**

### **Awareness and information**

The International Painful Bladder Foundation raises awareness of the disease worldwide and, at a time when insights and definitions are changing rapidly, provides high quality, up-to-date information on the latest developments in the field of diagnosis and treatment of IC and associated disorders through its website, newsletter, congress booths, publications and presentations. IC centres are now springing up around the world and more patients getting diagnosed. However, there are still countries around the world where IC is unknown and where IC is not a registered disorder.

During 2007, the IPBF website and other educational materials were further developed and kept updated. The IPBF website is maintained and continually updated by its webmaster. The website is frequently described as a “mine of information”. The materials including the brochure are produced in the simplest way possible so as to allow regular updating.

The CD Rom concept developed in 2006 was a great success in 2007. In 2007, the IPBF distributed around 1500 of these, not only at its congress booths but also at any other meetings where the opportunity presented itself.

The IPBF had a new leaflet in Hindi developed by a board member to use for its website this year and a new toilet card in German designed for the EAU congress booth in Berlin. The question list concerning the possible existence of associated disorders in IC patients was extended and is used by both doctors and patients.

During 2007 the IPBF included information leaflets from many different support groups on our congress booths.

The e-newsletter continues to be a success. The IPBF currently has around 4000 subscribers to its e-newsletter (approx 4x a year). 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 passed on to a much wider audience. In 2007 five newsletters were produced in January, March, June, September and December.

### **Capacity building**

The IPBF also helps new (local) patient support groups get started, and keeps the 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.

### **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 and criteria, the IPBF puts forward the viewpoints of the patients and patient organisations and the impact on these groups and consequences for the patient of changes. It also endeavours to create awareness of the fact that perceptions of a diseases differ greatly from culture to culture around the world. It is currently endeavouring to ensure that any new definitions accurately reflect the disease as experienced by the patient. Where necessary it carries out surveys to gain better insight.

The IPBF coordinates between all stakeholders involved in IC so as to help to create global cooperation and collaboration, since this is in the interests of the patients.

In the past year, the IPBF has served as a stable factor internationally in the IC world.

### **Memberships**

The IPBF has played an active role in the umbrella organisations Eurordis and IAPO thereby raising the profile of IC as a Rare Disease 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 organizations.

### **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. At the present time this is urge/urgency. Finding the cause(s) of this devastating problem could lead to new drugs that would greatly improve the quality of life for patients. The IPBF questionnaire survey on diagnosis and treatment was an ongoing project throughout 2007.

## **Support for patients**

The IPBF receives many letters and phone calls from patients in distress. Where necessary, the IPBF medical advisory board is called in to provide further information.

## **Projects undertaken by the IPBF in 2007**

The IPBF played an active role in the field of IC throughout 2007. Much of its work involves continual international consultation, discussion, provision and exchange of information as well as specific projects. During 2007 its activities included the following:

### **1. European Association of Urology annual congress, 21-24 March 2007, Berlin, Germany**

The IPBF was once again given complimentary booth space by the EAU. A large amount of information material was distributed, courses and abstract sessions were attended and the IPBF received many requests for newsletters. A review of the meeting was placed on the website including abstracts on IC presented at the meeting.

### **2. International Consultations on IC Japan conference Kyoto, Japan. 23-25 March 2007.**

The IPBF was represented at this international consultation meeting by board member Nagendra Mishra MD. This meeting was held for the purpose of discussing nomenclature and new definitions for interstitial cystitis.

### **3. International Alliance Patients Organizations annual conference on Patient-Centred Healthcare + AGM, 30 March 2007, United Nations, New York, USA**

Representatives of IAPO member organizations from around the world including the IPBF, United Nations NGO Health Committee members, healthcare professionals, academics, pharma representatives and other stakeholders converged on the United Nations in New York on 30 March 2007 for a day-long landmark meeting. The meeting successfully raised awareness of Patient-Centred Healthcare (PCH) at an international level, generated considerable support for the patient-led IAPO Declaration on Patient-Centred Healthcare and produced a number of recommendations for future action.

### **4. EURORDIS annual membership conference, 4-5 May 2007, Paris, France.**

The IPBF, an associate member of EURORDIS, attended the special 10<sup>th</sup> anniversary annual conference in Paris organized by Eurordis and Alliance Maladies Rares with the main theme of 'Gaining access to rare disease research resources'. It included a gala reception at which European MEP Françoise Grossetete spoke on rare disease legislation and the European Parliament.

### **5. American Urological Association (AUA) annual conference, 19-24 May 2007, Anaheim, USA**

Throughout the AUA conference in Anaheim, a main topic of conversation and behind-the-scenes discussions between IC experts, including the patient representatives attending the conference, was the issue of nomenclature ("what are we supposed to call this disease?" "Is it essential to change the name right at this moment?") and the complex problem of finding a usable definition for both research and clinical diagnosis. During the conference, 27 abstracts were presented on studies that directly or indirectly concerned PBS/IC.

### **6. International Continence Society Annual conference, 20-24 August 2007, Rotterdam, Netherlands.**

The IPBF was kindly given a complimentary booth by the ICS where it received an unprecedented number of visitors from all branches of healthcare. The IPBF treasurer, Florentina Ferreyra and two other patients from Mexico came to assist and gain experience. The IPBF promoted the new DVD on living with IC from the British COB Foundation and 50 copies of this were distributed during the workshop on PBS/IC. The IPBF also distributed COB Foundation information packs from the booth as well as leaflets from other support groups. This was so successful that we plan to do the same at the EAU congress in Milan in 2008.

**7. Societe Internationale d'Urologie (SIU), 2-6 September 2007, Paris France.**

In 2007 the IPBF had a complimentary booth for the first time at the SIU conference and shared this with the French IC support group (AFCI). Here at SIU we made many new contacts from developing countries, including Africa where we had few contacts until now. We received many requests from these new countries to join our mailing list.

**8. European Commission Conference on Rare Diseases Research, Brussels, 13 September.**

The IPBF was represented at this research conference by its chairman who was kindly sponsored by the European Commission. The aim of this top EU conference attended by government authorities, research institutes, industry, doctors and patients was to promote Rare Diseases as a priority of the European Union's political research agenda, to increase the visibility of Rare Diseases research, to raise awareness at the level of Member States and European Parliament of research needs in this field, to provide the Rare Diseases community with the opportunity to express their needs in terms of research in the context of the 7<sup>th</sup> Research Framework Programme (FP7), strengthening at the same time dialogue between stakeholders and the European Commission. It was emphasised that patient organisations for rare diseases can potentially play an important role in research programmes.

**9. European Conference on Rare Diseases for patients, 27-28 November 2007, Lisbon, Portugal**

This event was organised by the European Organisation for Rare Diseases (EURORDIS) and nine partners, under the patronage of the Portuguese Ministry of Health in the context of the Portuguese EU Council Presidency and was supported by the Public Health Programme of the European Commission DG SANCO. The conference, attended by the IPBF, was a unique opportunity for patients, healthcare professionals, policymakers and industry representatives to interact with decision-makers from the European Commission and member states and debate on key policies and actions aimed at improving the lives of people affected by rare diseases. The IPBF is trying to create awareness of IC among the rare disease organisations.

An extra day in Lisbon was included to allow for a meeting with the president of the Portuguese Urological Association which is planning to set up a website including for PBS/IC patients in Portugal. It was agreed that the IPBF would provide the information for this which would then be translated and adapted by them into Portuguese.

**10. IAPO seminar on Public Health and Intellectual Property, 6 November 2007, Geneva.**

Two IPBF board members (Jane Meijlink and Nagendra Mishra) were invited by IAPO to participate in this complex seminar aimed at educating patient representatives on the work of the IGWG and the issue of research for neglected diseases and to consider what role patient organizations can play in relation to the work of the IGWG and the area of neglected diseases. The seminar coincided with the 2<sup>nd</sup> meeting of the WHO Intergovernmental Working Group (IGWG)

## **11. NIH/NIDDK meeting: Redefining the Chronic Pelvic Pain Syndrome**

13-14 December 2007, Baltimore.

This meeting was convened by the NIDDK to discuss definitions for the purpose of its holistic MAPP project. Attendance was restricted to 40, but included the IPBF chairman. The main aims of this workshop were to discuss the disease definitions and diagnostic protocols of the major Chronic Pelvic Pain Co-Morbid Disorders (Interstitial Cystitis, Chronic Prostatitis, Fibromyalgia, Chronic Fatigue Syndrome and Irritable Bowel Syndrome); to discuss interrelationships among these disorders; to identify common symptomatology; to discuss methodology for a comprehensive diagnostic evaluation of persons with these symptoms to ensure a complete evaluation for all relevant co-morbidities. The patient advocates played an active and important role.

### **2007 a success**

2007 was a successful year for the new foundation. The newsletter is proving a great success and the website reviews of conferences and symposia and summaries of new research 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 focal point in a difficult area of health. During 2007, it worked intensively to protect and promote the interests of patients with IC around the world particularly in the important area of criteria, definitions and nomenclature and will continue to do so in 2008.