

# Annual Report of the International Painful Bladder Foundation (IPBF) for the year 2010

## **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 (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 2010**

The International Painful Bladder Foundation once again played an active international role in the year 2010. Much of its work involved international consultation, discussion, education including the provision and exchange of information, giving presentations, as well as specific projects.

During 2010, the IPBF's activities included the following:

#### **Awareness and information**

In 2010 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 2010, the IPBF website and other information and educational materials were further developed and 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 and at the ESSIC annual meeting in Antwerp. An additional chapter was added to the IPBF brochure (on fatigue) and the brochure fully updated. This brochure was once again highly popular in 2010. During 2010 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 2010. 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. Numbers visiting the website steadily increased during 2010.

The IPBF e-Newsletter continues to be a success. The IPBF currently has well 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 2010 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 2010 five e-Newsletters were produced in January, March, June, September and November. 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 2010 can be accessed on the website:

[January 2010:](#)

[March 2010](#)

[June 2010](#)

[September 2010](#)

[November 2010](#)

### **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 2010, 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. The IPBF does its best to provide especially the new support groups with as much support and exposure as possible. This encourages local medical professionals to work with the patient support group.

### **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 2010, the IPBF was continually in touch with all parties involved in guidelines, definitions and terminology. 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 2010 the IPBF once again played an active role in the umbrella organisations Eurordis and IAPO. In addition, the IPBF worked actively in 2010 as an associate of the Continence Promotion Committee of the International Continence Society (ICS), attending its committee meetings.

### **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 2010 we were invited to screen new symptom scores and new 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 2010. 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 2010: Bioniche Pharma Group Ltd, Oxyor bv and private donors. The IPBF is dependent on donations and the funding received in 2010 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 credit crisis. This is affecting not only the IPBF but also IC support groups worldwide.

### **SPECIFIC PROJECTS UNDERTAKEN BY THE IPBF IN 2010**

#### **1. REVIEW OF THE SOCIETY FOR URODYNAMICS & FEMALE UROLOGY (SUFU) WINTER MEETING, 23-27 FEBRUARY 2010, TAMPA-ST. PETERSBURG, FLORIDA, USA.**

A review of the meeting was written for the website.

[http://www.painful-bladder.org/pdf/2010\\_SUFU\\_Tampa.pdf](http://www.painful-bladder.org/pdf/2010_SUFU_Tampa.pdf)

#### **2. EUROPEAN ASSOCIATION OF UROLOGY (EAU) 25TH ANNUAL CONGRESS HELD BARCELONA, SPAIN - 16-20 APRIL 2010**

The IPBF chair attended this meeting. The IPBF's full review of posters and presentations on IC/PBS and related topics presented at the EAU 2010 congress can be found on the IPBF website at:

[http://www.painful-bladder.org/pdf/2010\\_EAU\\_Barcelona.pdf](http://www.painful-bladder.org/pdf/2010_EAU_Barcelona.pdf)

This was a dramatic occasion since the Icelandic volcano meant that, like so many others, the IPBF chairman was marooned in Barcelona with all flights cancelled and with the added disadvantage of having reduced mobility and being on crutches. She was happily rescued by Astellas Pharma who kindly gave her the last seat in the bus they had chartered back to the Netherlands.

#### **3. ESSIC ANNUAL MEETING 2010, ANTWERP, BELGIUM, 20-22 MAY 2010.**

This meeting was attended by the IPBF chair who also gave a presentation on Fatigue related to ICF/PBS.

A review of the meeting can be found on the IPBF website at:

[http://www.painful-bladder.org/pdf/2010\\_ESSIC\\_Antwerp.pdf](http://www.painful-bladder.org/pdf/2010_ESSIC_Antwerp.pdf)

The material from the presentation was afterwards formed into an additional chapter for the IPBF brochure.

#### **4. AUA ANNUAL MEETING HELD 29 MAY-3 JUNE 2010, SAN FRANCISCO, USA**

This meeting was attended. The IPBF compiled a detailed review of IC/PBS presentations and posters at the American Urological Association annual meeting 2010. The AUA annual meeting 2010 could be considered a landmark meeting for IC with its unprecedented number of presentations and even prestigious plenary sessions devoted to the topic, underlining the attention this syndrome is currently receiving. The review of this meeting can be found on the IPBF website at:

[http://www.painful-bladder.org/pdf/2010\\_AUA\\_SanFrancisco.pdf](http://www.painful-bladder.org/pdf/2010_AUA_SanFrancisco.pdf)

#### **5. THE JOINT ANNUAL SCIENTIFIC MEETING OF THE INTERNATIONAL CONTINENCE SOCIETY (ICS) AND THE INTERNATIONAL UROGYNECOLOGICAL ASSOCIATION (IUGA), TORONTO, CANADA, 23-27 AUGUST 2010**

The International Continence Society (ICS) is a unique, multidisciplinary society whose members consist of urologists, (uro)gynaecologists, neurologists, gastroenterologists, geriatricians, paediatricians, biomechanical engineers, physicists, nurses and physiotherapists from all parts of the world. All of these people have a special interest in different aspects of urinary and faecal incontinence and the function and dysfunction of the pelvic floor, including pelvic, bowel, bladder and perineal pain. This year's conference

being a joint meeting with IUGA meant that a larger number of gynaecologists were also present. It was therefore an ideal conference at which to organise a booth. And indeed this complimentary IPBF booth was a huge success with great interest shown by delegates. A detailed review by the IPBF of scientific presentations related to IC/PBS can be found at:

[http://www.painful-bladder.org/pdf/2010 ICS IUGA Toronto.pdf](http://www.painful-bladder.org/pdf/2010%20ICS%20IUGA%20Toronto.pdf)

## **6. BOOK CHAPTER**

The IPBF chair was invited to contribute a chapter on the Patient Perspective for a book for clinicians edited by ESSIC to be published in the summer of 2011 by Springer.

### **2010 a successful and active year**

2010 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.

The chairman would like to thank all IPBF board members for their hard work, help, advice and input during the year 2010 despite their personal medical problems and to thank all IC support groups for their feedback and cooperation. Board member Nagendra Mishra MD is to be congratulated on the setting up of a website with patient information and an IC/PBS Society of India. 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 found herself and many members of her support group at the heart of a major earthquake in Christchurch New Zealand in 2010 and despite substantial damage to her own home and continuing tremors managed to rally her IC troops with a patient meeting in Christchurch. Toby Meijlink worked hard throughout the year on IPBF administration and ran the IPBF booth at the ICS annual meeting in Toronto. 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.*