

# Annual Report of the International Painful Bladder Foundation (IPBF) for the year 2009

## 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 2009

The International Painful Bladder Foundation once again played an active role in the year 2009.

Much of its work involved international consultation, discussion, the provision and exchange of information as well as specific projects. During 2009, the IPBF's activities included the following:

## Awareness and information

In 2009 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 2009, 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 all other meetings where any kind of info table was available.

During 2009 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 2009. 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 2009.

In the section on associated disorders, the IPBF has an excellent book by Dr Joop P. van de Merwe on Sjögren's Syndrome, which can be downloaded chapter by chapter, and is continually being updated.

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 2009 the IPBF received many requests from patient support groups to use items from the IPBF e-Newsletter in their own newsletter. In 2009 four e-Newsletters were produced in January/February, 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 2009 can be accessed on the website:

January/February 2009:

[http://www.painful-bladder.org/pdf/2009\\_02\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2009_02_Newsletter.pdf)

April 2009:

[http://www.painful-bladder.org/pdf/2009\\_04\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2009_04_Newsletter.pdf)

July 2009:

[http://www.painful-bladder.org/pdf/2009\\_07\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2009_07_Newsletter.pdf)

October 2009:

[http://www.painful-bladder.org/pdf/2009\\_10\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2009_10_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 2009, 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. There is now a new patient support group in Portugal and a website for IC/PBS and overactive bladder patients in Romania.

### 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 2009, the IPBF was continually in touch with all parties involved. 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 2009 the IPBF played an active role in the umbrella organisations Eurordis and IAPO and was represented on the organising committee of the IAPO 4th Global Patients Congress. In addition, the IPBF worked

actively in 2009 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 2009. 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 2009: Astellas Pharma bv, Bioniche Pharma Group Ltd, Oxyor bv and private donors. The IPBF is dependent on donations and the funding received in 2009 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 2009

##### 1. EUROPEAN ASSOCIATION OF UROLOGY (EAU) 24TH ANNUAL CONGRESS HELD 17-21 MARCH 2009, IN STOCKHOLM, SWEDEN

The IPBF's full review of posters and presentations on IC/PBS and related topics presented at the EAU 2009 congress can be found on the IPBF website at:

[http://www.painful-bladder.org/pdf/2009\\_EAU\\_Stockholm.pdf](http://www.painful-bladder.org/pdf/2009_EAU_Stockholm.pdf)

##### 2. AUA ANNUAL MEETING HELD 25-30 APRIL 2009, IN CHICAGO, ILLINOIS, USA

The IPBF compiled a detailed review of IC/PBS presentations and posters at the American Urological Association annual meeting 2009. This review included plenary/society presentations, selected abstracts, a review of the course on IC/PBS given by Dr Robert Moldwin. This review can be found on the IPBF website at:

[http://www.painful-bladder.org/pdf/2009\\_AUA\\_Chicago.pdf](http://www.painful-bladder.org/pdf/2009_AUA_Chicago.pdf)

### 3. ESSIC ANNUAL MEETING, HELD IN GÖTEGORG, SWEDEN 4-6 JUNE 2009

The 2009 annual meeting of the European Society for the Study of IC/PBS (ESSIC) was held in the Swedish city of Göteborg and was attended by 52 participants. While the Thursday sessions were reserved for members, sessions on Friday and Saturday morning were open to non-members. The public sessions included a Symposium on Hunner's lesion (ulcer) and Treatment of Bladder Pain: a Practical Approach. The IPBF was represented by its chairman Jane Meijlink who also gave a presentation on historical aspects of IC as a background to the Hunner's Symposium at this meeting. A review of this meeting was given in the IPBF April e-Newsletter: [http://www.painful-bladder.org/pdf/2009\\_04\\_Newsletter.pdf](http://www.painful-bladder.org/pdf/2009_04_Newsletter.pdf)

### 4. 39TH ANNUAL MEETING OF THE INTERNATIONAL CONTINENCE SOCIETY (ICS) HELD IN SAN FRANCISCO, USA, 29 SEPTEMBER TO 3 OCTOBER 2009

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. 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/2009\\_IC\\_SanFrancisco.pdf](http://www.painful-bladder.org/pdf/2009_IC_SanFrancisco.pdf)

### 5. CONVERGENCES IN PELVIPERINEAL PAIN (CONVERGENCES PP) 16-18 December 2009, Nantes, France

Convergences PP was a unique, bilingual, multidisciplinary conference on pelvipерineal pain co-organised by SIFUD, AFU, CNGOF, PUGO/IASP, SCGP, SFETD, SIREPP, SNFCP and SOFMER at the International Congress Centre of Nantes in France. Several patient organizations engaged in this field were represented here, including the IPBF, and were kindly provided with complimentary information tables. The IPBF CD once again proved a great success. A review of this meeting is on the IPBF website at: [http://www.painful-bladder.org/pdf/2009\\_Convergences%20PP\\_Nantes.pdf](http://www.painful-bladder.org/pdf/2009_Convergences%20PP_Nantes.pdf)

### 2009 a successful and very active year

2009 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 2009 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 an IC/PBS Society of India that is currently working on an Indian Clinical Guideline.

#### Retirement of Dr Leroy Nyberg from the NIDDK

Dr Leroy M. Nyberg, Urology director at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH) and a familiar face to doctors and patient advocates around the globe, retired at the beginning of September 2009. Dr Nyberg worked closely with the ICA to raise awareness of IC and get research off the ground within the NIH. This had an impact worldwide and we are exceedingly grateful to him for his dedication, empathy and support for IC patients.

*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.*