

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2022

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 Zámecník, 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

Webmaster: Joop P. van de Merwe, MD

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 address is located in Naarden. In all legal issues, Dutch law prevails. The Foundation has fiscal charitable status in the Netherlands, Charity Fiscal Number: 8168.41.597.

OBJECTIVES AND MISSION OF THE IPBF:

The International Painful Bladder Foundation is a voluntary non-profit organisation with the objective of raising awareness of Hypersensitive Bladder, Interstitial Cystitis, Bladder Pain Syndrome and Hunner Lesion worldwide among patients, health professionals and the general public by means of its website, e-newsletter to over 4500 patients and health professionals worldwide, publications, presentations and congress booths, with the aim of ensuring that IC/BPS/HSB 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 and participates in research, participates in international discussions and panels 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 hypersensitive bladder, interstitial cystitis, bladder pain syndrome, Hunner Lesion, chronic pelvic pain syndromes and associated disorders;
- To increase awareness and knowledge of hypersensitive bladder, interstitial cystitis, bladder pain syndrome, Hunner lesion, 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 and participate in scientific research;
- To promote international cooperation between people involved in interstitial cystitis/bladder pain syndrome, hypersensitive bladder, chronic pelvic pain syndromes 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 2022

2022 was a busy year for the IPBF. A spin-off of the Covid period was that an increasing amount of the IPBF's work moved online during 2022. This included major congresses that were now hybrid and could be attended virtually, as well as innumerable webinars in the field of IC/BPS. The IPBF's participation in IMI-PainCare continued throughout the year and included virtual presentations. The IPBF also actively participated in the online international IC/BPS patient advocacy meetings (currently held at least twice a year) and in ESSIC webinars. The IPBF took part in AUA, ICS and EAU congresses virtually in 2022.

IPBF E-NEWSLETTER AND RESEARCH UPDATE

In February 2022, it was decided to publish the eNewsletters and the Research Updates in separate pdf documents to facilitate downloading and reading. The eNewsletters and Research Updates were published in February, May and September 2022 and available on the IPBF website.

In 2022 we focused our newsletters on looking critically at guidelines, pinpointing where the problems lie and what is causing the most confusion since consensus on anything seems very far away and this is not helping research into new treatment. There is currently a need for international scientific discussions, in-person, virtual or hybrid, in order to move forward with better coordination of research, guidelines, diagnosis and treatment. We also stressed throughout the year that affordability is going to be a key issue in the coming years. No patient and no health system can afford the current trial & error. Better, more accurate diagnosis and treatment tailored to the individual patient can help to avoid this kind of wastage. While health issues are difficult from an economic point of view now, in the coming few years they could be even more difficult.

VIRTUAL MEETINGS OF INTERNATIONAL IC/BPS PATIENT ADVOCATES HELD ON 24 JUNE 2022 AND 10 DECEMBER 2022: CAPACITY BUILDING

Thanks to the hard work of Mathilde Scholtes (Netherlands) assisted by Balaka Basu (India), IC/BPS patient advocates now have the opportunity to discuss current problems and get updated in online Zoom meetings approximately twice a year. This meeting opportunity is really helpful since many smaller support groups have been struggling during the Covid period. It is also a chance for the more experienced patient advocates to help the new generation of advocates to build up their knowledge.

ESSIC FOCUSING WEBINARS

ESSIC (International Society for the Study of IC/BPS) organised a number of webinars which IPBF attended and actively participated in. In 2022, these included Behavioural management & diet, Psychology (in which IPBF chair Jane Meijlink gave a presentation discussing the psychosocial consequences of IC/BPS) and Sexuality. The session on Psychology led to Professor Dean Tripp from Queen's University Canada setting up an international study with patient surveys with a focus on sleep deprivation.

NATIONAL INSTITUTES OF HEALTH (NIH)/NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) VIRTUAL MEETING OCTOBER 17–18, 2022: "RESEARCH ADVANCES FOR UROLOGIC CHRONIC PELVIC PAIN SYNDROME: INFORMING THE NEXT GENERATION OF CLINICAL STUDIES"

This keynote virtual meeting organized by the NIH/NIDDK in the USA and attended by the IPBF provided a "global" forum for the exchange of new insights into the Urologic Chronic Pelvic Pain Syndrome (UCPPS) - which encompasses both IC/BPS and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) - on which the NIDDK's Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network was based. A central goal of the meeting was to promote the translation of new findings into future, evidence-based clinical trials for UCPPS that will hopefully ultimately improve patient care. The meeting highlighted findings from the MAPP Network and others working in the field as well as advances in other related areas. Scientific themes included phenotypic subgrouping strategies for targeted interventions, mechanistic insights in support of new

targets and phenotypes, improved evidence-based definitions and outcome measures and designs for clinical trials informed by new research insights. There were also breakout sessions that facilitated active participation by all attendees. This “virtual” format allowed many health professionals and patients/patient advocates, who would not otherwise have been able to travel in these difficult times, not simply to attend but also actively participate.

DUTCH SYMPOSIUM ON INFLAMMATORY BLADDER DISORDERS, AMSTERDAM 7th OCTOBER 2022

This symposium on inflammatory bladder disorders was held in Amsterdam, and the IPBF was permitted to attend. It was a unique urological programme looking at the whole field of “cystitis” – bladder inflammation – including interstitial cystitis, ketamine cystitis, eosinophilic cystitis, radiation cystitis, haemorrhagic cystitis induced by the BK virus or chemo-therapy and the condition known as cystitis glandularis.

GIBS INDIA

The GIBS society from India organised numerous webinars and virtual or hybrid conferences, often in combination with urology and gynaecology societies from different countries. Most were attended virtually by the IPBF and gave extensive insight into the situation regarding diagnosis, treatment and awareness of IC/BPS in other (developing) countries.

The GIBS 7th Annual Congress on IC/BPS was held 27-28 August 2022, at Kokilaben Dhirubhai Ambani hospital and medical research institute in Mumbai, India. Due to the ongoing impact of Covid and travel problems, this was a hybrid conference with many people participating or presenting online. There were three excellent patient presentations by patient advocates Balaka Basu from India, Mathilde Scholtes from the Netherlands and Jill Osborne from the USA, with Neelanjana Singh speaking on Diet Therapy.

HYBRID BRAINSTORMING SESSION ON INTRACTABLE IC/BPS HELD IN AHMEDABAD, INDIA, 20-21 SEPTEMBER 2022

A hybrid brainstorming meeting of urologists and urogynaecologists from different parts of India with an interest in IC/BPS was held on 20 and 21 September 2022 in the city of Ahmedabad which lies to the west of India in the state of Gujarat, at which the topic of “intractable IC/BPS” was discussed. This event was organised by Bhaikaka University, Anand, India with IPBF Board Member Dr Nagendra Mishra playing a leading role and was also attended virtually by the IPBF Chair. During the meeting, various options were discussed for management of intractable IC/BPS.

IPBF PARTICIPATION IN THE IMI-PAINCARE RESEARCH CONSORTIUM

<https://www.imi-paincare.eu/>

The IMI-PainCare Research Consortium is composed of 40 participants from 14 countries; 6 are EFPIA (European Federation of Pharmaceutical Industries and Associations) participants with strong traditions in pain research and development, 23 are internationally renowned academic and clinical institutions, 5 are specialist SMEs with cutting-edge technologies, 3 are patient organizations and 3 are professional pain/anaesthesia societies.

The Consortium addresses three important topics:

- Patient reported outcome measures to improve management of acute and chronic pain (PROMPT);
- Pharmacological validation of functional pain biomarkers in healthy subjects and animals (BioPain);
- Improving translation in chronic pelvic pain (TRiPP) which includes endometriosis and IC/BPS.

The IPBF continued its participation as patient representative in this research project throughout 2022. IPBF Chair Jane Meijlink attended all monthly online meetings for both the clinical and pre-clinical research. She also gave a (virtual) presentation on Terminology, Definitions and Classification of IC/BPS at the IMI-Paincare General Assembly.

INTEGRATE-PAIN

<https://integrate-pain-domain-meeting.com/>

INTEGRATE-Pain: the “IMI-NIH Transatlantic Emphasis Group on Research and Translation-to-care Efforts for Pain,” was established by the NIH HEAL initiative and IMI-PainCare to foster cooperation and consensus in the field of pain research. Dedicated to improving the understanding, management, and treatment of pain, both teams have prioritized common opportunities in preclinical and clinical research, ultimately accelerating the

discovery and development of new non-addictive treatments and improving the management of pain. During 2022, the IPBF participated in a number of online meetings for INTEGRATE-Pain.

ICD-11

During 2022, the IPBF also took part in discussions concerning terminology and definitions proposed for ICD-11 (International Classification of Diseases).

INTERNATIONAL CONSULTATION ON INCONTINENCE - ICI GUIDELINE CHAPTER ON IC/BPS

IPBF chair Jane Meijlink participated throughout 2022 in the international committee chaired by Professor Philip Hanno on updating the ICI guideline chapter on IC/BPS which will be published in 2023.

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 the IPBF is very grateful for all the help and advice they provided during 2022. Many IC/BPS patients worldwide have been very worried about the impact of Covid on their bladder and its long-term impact on their general health and needed to discuss this with us. Patients have experienced difficulties in getting appointments for diagnostic investigations and treatment due to the consequences of the pandemic. These problems led to a global exchange of information on the topic between patient organisations.

SPECIAL THANKS TO SPONSORS AND DONORS

The IPBF would like to thank its sponsors in 2022. The IPBF is dependent on donations. Funding received in 2022 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, since the start of the Covid period and the economic difficulties experienced in many countries, it has been very difficult to obtain sponsoring in the field of rare diseases.

2022 A SUCCESSFUL AND ACTIVE YEAR

2022 was again 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 throughout the Covid pandemic.

The Chairman would like to thank all IPBF board members for their hard work, help, advice and input during the year 2022 and to thank all IC/BPS support groups for their feedback and cooperation. Many thanks are also due to our webmaster Joop P. van de Merwe, MD, for maintaining the IPBF website throughout the year, to all members of our Medical Advisory Board and many other health professionals who have been very generous with their help and advice.

INCOME AND EXPENDITURE 2022 SUMMARY

Sponsor funding and donations received:	€ 10,688.79
General operating expenses:	€ 8,835.70
Information material, IT, website, project and conference/meeting expenses:	€ 2,687.75

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. While the IPBF endeavours to ensure that all information it provides is correct and accurate, it does not accept any liability for errors or inaccuracies.

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