

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2023

IPBF Board:

Chairman: Jane Meijlink

Secretary/Treasurer: Toby Meijlink

Member: Nagendra Mishra MD

Member: Dorothy Milne RN

Member: Florentina Ferreyra

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 **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 2023

IPBF WEBSITE

Our webmaster for the past 20 years, Dr Joop P. van de Merwe, had to step down due to health problems. We are most grateful to him for all his work, support and advice over almost two decades. Niek Meijlink agreed to take on the task of creating a new website with up-to-date software, expected to be completed in 2024, and to serve as webmaster. For this purpose, a start was made on screening and updating all information on the website.

WEBINARS

The IPBF was represented at multiple webinars, web discussions and hybrid conferences throughout 2023, including the AUA annual meeting, IMI-Paincare and IMI-Prefer, eUrogen, ESSIC, GIBS (from India), EAU, ICS annual meeting, IASP, EFIC, IAPO, PAE, IUGA, ICA, International IC/BPS Patient Advocates, and more.

EFIC WEBINAR ON CHRONIC PRIMARY PAIN IN ICD-11, 28 April 2023

On 28 April, the IPBF chair attended a webinar organised by EFIC on chronic primary pain where the aim was to give an overview of the definition and new classification under ICD-11 as well as provide information on the assessment and management of chronic primary pain. Panellists were Prof. Rolf-Detlef Treede, Heidelberg University, Dr Beatrice Kowisi, Philipps-University Marburg and Prof. Paul Cameron, EFIC Advocacy Committee Chair.

Online attendees were able to actively ask questions via the Q&A box and the IPBF asked a number of questions regarding how IC/BPS fits into chronic primary pain classification where it is referred to as chronic primary bladder pain syndrome. One had the distinct feeling that it does not really fit in, that it might be a square peg in a round hole, that there are many unanswered questions and that we have to be exceedingly alert as to where all of this may be leading from the point of view of IC/BPS.

VIRTUAL MEETINGS OF INTERNATIONAL IC/BPS PATIENT ADVOCATES: CAPACITY BUILDING AND KNOWLEDGE TRANSFER

Thanks to the continued efforts of Mathilde Scholtes (Netherlands) assisted by Balaka Basu (India), IC/BPS patient advocates now have the opportunity to discuss current IC/BPS issues and get updated in online Zoom meetings approximately twice a year. These meetings and networking opportunities are really helpful since many smaller support groups do not have the resources to attend live international conferences. It is also a chance for the more experienced patient advocates to help the new generation of advocates to build up their knowledge. The IPBF chair Jane Meijlink and IPBF Board Member Dot Milne from New Zealand participate in these meeting. There is frequent email contact between the patient advocates throughout the year.

PRESENTATIONS

- EUROPEAN ASSOCIATION OF UROLOGY (EAU) 2024 CONGRESS IN MILAN - IPBF PRESENTATION IN EAU PATIENT DAY SESSION: FRIDAY 10 MARCH

This was the third EAU Congress Patient Day where patient advocates can make their voice heard and also present work at the Patient Poster Session. One session concerned Cystitis – with two presentations focusing on IC/BPS - aimed at enabling delegates to differentiate between the different types of cystitis and their treatment options, in addition to gaining insight into a patient’s care pathway. All presentations were recorded and are available as webcasts on the EAU website: <https://urosource.uroweb.org/search?sessionId=13548>. IPBF chair Jane Meijlink spoke on the topic of Taxonomy and Nomenclature, terms that cover the whole field of standard terminology, definitions, criteria and classification, the history of which in the field of IC/BPS could fill a bookcase! Since the purpose of standard terminology is to identify and accurately describe a disease or disorder, guide research, diagnosis and treatment, enable information and research to be shared globally without confusion, facilitate consistency in electronic systems, for data retrieval, healthcare reimbursement, benefits etc, and also to enable patients to recognise their diagnosis and seek relevant information, the speaker concluded that these aims have in no way been achieved and all we have is confusion worldwide! She added that in today’s world, it seems irresponsible and certainly patient-unfriendly to keep changing the name of a disease. It is time for global consensus on both the name and the definition + a truly patient-centric approach.

ESSIC IC/BPS CONGRESS HELD IN NEW YORK 6-8 JULY 2023

After several postponements due to Covid, the ESSIC congress was held 6-8 July 2023 in New York, USA. The meeting included keynote lectures, debates, panel discussions etc on IC/BPS by top speakers, as well as networking events. The IPBF Chair gave a recorded video presentation on the role of the patient and patient organisations in research.

GUIDELINE PARTICIPATION

ICI 7 2023 – CHAPTER 18: Guideline on IC/BPS

Incontinence 7th Edition (ICI 7) forms a comprehensive reference work covering the entire field of continence for all disciplines in 2023. While it is based on the ICI-ICS consultation held in 2021, publication was delayed by Covid. **Chapter 18 covers Interstitial Cystitis / Bladder Pain Syndrome** and serves as a clinical and research guideline. This chapter covers history, recommendations for terminology, patient perspective, epidemiology, etiology, pathology, diagnosis, confusable disorders, classification and phenotyping, conservative treatment, oral treatment, intravesical treatment, botulinum toxin, neuromodulation, surgical therapy, outcome assessment, impact on quality of life, etc. The international committee working on this IC/BPS chapter was chaired by Philip Hanno, (United States), and included Mauro Cervigni (Italy), Myung-Soo Choo, (Republic of Korea), J. Quentin Clemens, (United States), Daniela Gold, (Austria), Ming Huei Lee, (Taiwan), Sachin Malde, (United Kingdom), Jane Meijlink, (IPBF Netherlands), Michael Samarinas, (Greece), Tomohiro Ueda (Japan). The IPBF Chair represented the global patients throughout this project.

ESSIC GUIDELINE

The ESSIC Guideline team was set up IN 2023 and included the IPBF to represent the patient perspective. This will continue during 2024 and will be presented in Kyoto, Japan in August 2024 at the joint ICICJ/ESSIC conference.

IPBF E-NEWSLETTER AND IPBF RESEARCH UPDATE

To facilitate downloading of the Research Update, we have now placed the **IPBF eNewsletter** and **IPBF Research Update** in separate pdf files online. Both can be accessed via the IPBF home page: <https://www.painful-bladder.org/>

RESEARCH PARTICIPATION

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 in 2023. IPBF Chair Jane Meijlink attended all monthly online meetings for both the clinical and pre-clinical research and was a co-author of several IMI-Paincare journal publications, conference abstracts and poster presentations. The Research Consortium officially came to an end in mid 2023 but work on publications continued.

EAU PATIENT OFFICE – ePAG MEMBERSHIP

The European Association of Urology (EAU) Patient Office was set up in 2021 and is therefore still in a relatively early stage of its development. Nevertheless, this Patient Office now has a Chair, Prof. Eamonn Rogers, and more recently a Patient Office Board. It also has a European Patient Advocacy Group (ePAG), see <https://patients.uroweb.org/patient-advocacy/>. Jane Meijlink, IPBF Chair, was invited to become an ePAG member. The European Patient Advocacy Groups represent the patient voice in the European Reference Networks (ERNs). ePAG meetings are held regularly and can be attended either live or virtually.

SUPPORT FOR PATIENTS

The IPBF receives many emails 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 2023.

SPECIAL THANKS TO SPONSORS AND DONORS

The IPBF would like to thank its sponsors in 2023. The IPBF is dependent on donations. Funding received in 2023 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 Covid period and the economic difficulties experienced in many countries, it has been very difficult to obtain sponsoring in the field of rare and complex diseases such as IC/BPS. The IPBF is particularly grateful to Goodlife Pharma for assisting with travel and accommodation for EAU 2024 in Milan.

2023 A SUCCESSFUL AND ACTIVE YEAR

2023 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 2023 and to thank all IC/BPS support groups for their feedback and cooperation. Many thanks are also due 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 2023 SUMMARY

Sponsor funding and donations received:	€ 9,100.00
General operating expenses:	€ 4,822.84
Information material, IT, website, project and conference/meeting expenses:	€ 4,586.54

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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