

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2021

Website:

<https://www.painful-bladder.org/>

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

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 international 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 2021

With the Covid pandemic continuing throughout the year, in-person conferences were again largely cancelled and moved online. While everyone misses the networking opportunities of in-person contact, virtual presentations, webinars, meetings and conferences allow far more patients to actively participate both nationally and internationally. It has been a great learning opportunity for patient advocates. There were innumerable online meetings and webinars throughout 2021, sometimes two or more in one day, making the work of the IPBF exceptionally busy but allowing us to follow activities and the current situation in the field of IC/BPS in several developing countries. The IPBF attended all relevant virtual congresses during 2021.

AWARENESS AND INFORMATION

In 2021, the IPBF continued to focus attention on raising awareness of IC/BPS and associated disorders worldwide at all levels (patients, professionals, health authorities, pharma industry) and provided high quality, up-to-date information on the latest insights, developments and research in the field of diagnosis and treatment of IC/BPS, HSB, Hunner Lesion, chronic pelvic pain syndromes and associated disorders through its website, e-Newsletter, publications and presentations and active participation in committees and working groups.

IPBF E-NEWSLETTER AND RESEARCH UPDATE

The IPBF e-Newsletter and Research Update continues to be a success and the IPBF received many requests from both patients and health providers to be added to the mailing list. The IPBF currently has well over 4500 subscribers to its e-Newsletter. These subscribers come from the patient world, family doctors, medical specialists in different specialisms, continence nurses, pelvic floor physiotherapists and pharma industry, many of whom in turn circulate the newsletter to their networks. The patient support groups often use the information for their own newsletters, particularly research items. In this way the information provided gets circulated to a much wider readership. E-Newsletters were produced in March, June and October 2021 and distributed worldwide by email. [Click here.](#)

CAPACITY BUILDING

On request, the IPBF also helps new (local) patient support groups get started. In 2021, IPBF Board members continued to help new support groups in all parts of the world. The IPBF keeps patient organisations updated on the latest (scientific) developments which they can adapt to use in their own newsletters. It also endeavours to ensure that support groups are aware of information (books, videos, CDs, web material, blogs, etc) produced by other patient organisations. Furthermore, the IPBF is doing everything possible to pass on as much information as possible to the younger generation of patient advocates. COVID has accelerated a trend towards use of social media by support groups. Many

groups in different countries have had problems finding volunteers willing to take on any tasks to help keep the support group going. Anxiety about COVID and lockdowns have made this worse than usual.

PRESENTATIONS GIVEN

The IPBF gave a number of virtual presentations in 2021 including:

- IPBF virtual presentation on Sjögren's and IC/BPS

IPBF Chair Jane Meijlink was invited to give a pre-recorded video presentation on Sjögren's syndrome in patients who also have interstitial cystitis/bladder pain syndrome for the Southern Continence Forum held in Southampton, United Kingdom on 1 October 2021 for the nursing profession. It is encouraging to know that interest in this specific group of patients is being stimulated.

- BioFIT 21 Online Event: IPBF Panel Participation

The IPBF Chair was invited to take part in a panel session, moderated by Nick Hicks, at BioFIT 21 online event on 8 December discussing at what stage in the development of an R&D project should patient organisations qualify as partners. There is a general desire for increased involvement of patient organisations in collaborative healthcare projects, as they bring experience, knowledge and real-life assessment to the table. Questions dealt with by panel members included what are the benefits of creating partnerships that cross scientific, academic, advocacy and industry spheres? How early should patient organisations be involved in R&D efforts? How do patient organisations influence the way collaborations are carried? And what are the favoured R&D tools involving patients at research scale and what is their acceptance? A number of preparatory online meetings were also held in the months prior to the event itself.

IPBF AND GLOBAL ADVOCACY

Global patient advocacy is a key aspect of 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 or developments. In 2021, the IPBF once again emphasized the lack of reimbursement of treatment and the consequent unaffordability of essential treatment. The IPBF also continued to lobby for meaningful phenotyping to help ensure that the right patient gets the right medicine. The Foundation also lobbied for better methods of diagnosing a defective bladder lining.

INTERNATIONAL PATIENT ADVOCATES

- Online international meetings of patient advocates June and December 2021

A great advantage of the current shift to online communication due to the pandemic has been the initiative by the Dutch ICP and Interstitial Cystitis India to organise virtual global meetings of IC/BPS patient advocates in which the IPBF also participated in 2021. The virtual meeting held on 26 June 2021 was the second virtual opportunity for patient advocates from around the globe to meet to discuss the problems they are faced with and how these can be solved. This gives everyone a much better idea of what is happening at the grass roots. Patient representatives participating this time came from the Netherlands, India, France, Hungary, Israel, Spain, and the UK and each spoke about the current situation in their country and the impact of the COVID pandemic.

There was a short presentation by the IPBF chair on the issue of nomenclature and definitions, explaining what ICD-11 is with a brief look at its new classification concepts for chronic pain, and also taking a look at the new 2021 EAU guidelines on chronic pelvic pain. It was emphasised that is very important for the new generation of patient advocates to have a good knowledge and understanding of guidelines, classifications and criteria so as to be able to participate in projects and studies when required. The 3rd global IC/BPS patient advocacy meeting was once again held virtually on 11 December 2021, organized by Mathilde Scholtes (ICP Netherlands) and Balaka Basu (ICI India). 18 patient advocates participated from the Netherlands, India, Italy, Hungary, France, USA, Canada,

Spain, Denmark, Israel and the United Kingdom. Ten presentations from individual countries were followed by a round table discussion.

OTHER VIRTUAL CONFERENCES

The conferences the IPBF usually attends were all moved online again in 2021 and the IPBF participated in the virtual conferences of the American Urological Association, the European Association of Urology, the International Continence Society, the International Association for the Study of Pain, the ESSIC Masterclass and ESU Masterclass.

RESEARCH PARTICIPATION

- IPBF PARTICIPATION IN THE IMI-PAINCARE RESEARCH CONSORTIUM

The IPBF has been participating in the IMI-PainCare Research Consortium (<https://www.imi-paincare.eu/>) since it began in 2018. This 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/anesthesia 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).

The IMI-PainCare Research Consortium held its Annual General Assembly on 2-4 March 2021, conducted as a virtual meeting due to the Covid-19 pandemic. With the project now approximately halfway into the funding period, more than 70 consortium members, including the patient representatives for chronic pelvic pain, endometriosis and IC/BPS, together with IMI scientific officer Elisabetta Vaudano and the external ethics and scientific advisors, discussed exciting achievements and ongoing activities as well as the valuable input of the patient representatives Judy Birch, Lone Hummelshoj and Jane Meijlink. Read more: <https://www.imi-paincare.eu/NEWS/>

The IPBF attended 2 online discussion meetings every month during 2021 as well as a workshop 18-25 January, the IMI-PainCare general assembly online 2-4 March 2021 and interim results meetings 15 and 22 June. At a virtual meeting 5-7 October, 7 October was devoted to discussion of patient involvement.

A recent publication from this research group in 2021 is:

Nunez-Badinez P, De Leo Bianca, Laux-Biehlmann A, Hoffmann A, Zollner TM, Saunders P, Simitsidellis I, Charrua A, Cruz F, Gomez R, Tejada M, McMahon S, Lo Re L, Barthas F, Vincent K, Birch J, Meijlink J, Hummelshoj L, Sweeney P, Armstrong D, Treede R-D, Nagel J. [Preclinical models of endometriosis and interstitial cystitis/bladder pain syndrome: an Innovative Medicines Initiative-PainCare initiative to improve their value for translational research in pelvic pain](#). PAIN: September 2021 - Volume 162 - Issue 9 - p 2349-2365 doi: 10.1097/j.pain.0000000000002248

The IPBF is regularly consulted by medical researchers around the world. 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, including by giving presentations at conferences and workshops and through direct contact with medical professionals. IPBF board members are frequently consulted by research and guideline groups. The IPBF has been consulted by several pharma companies about the patient perspective in relation to development of new treatments for IC/BPS and to provide advice and information from the grass roots. The IPBF is also regularly consulted by Cochrane including in 2021.

PUBLICATIONS

The IPBF participated in the followed article published in 2021:

Ueda T, Hanno PM, Saito R, Meijlink JM, Yoshimura N. Current Understanding and Future Perspectives of Interstitial Cystitis/Bladder Pain Syndrome. Int Neurourol J. 2021 Jun;25(2):99-110. doi: 10.5213/inj.2142084.042. Epub 2021 Jun 30. PMID: 34218637; PMCID: PMC8255826.

ICD-11 DISCUSSIONS – INTERNATIONAL CLASSIFICATION OF DISEASES VERSION 11

The IPBF initiated and took part in an e-meeting in March with Professor Rolf-Detlef Treede and Dr Beatrice Korwisi followed by a further e-meeting in April which included several IC/BPS experts to discuss the classification of IC/BPS in ICD-11 and specifically in the new chronic pain section.

INTERNATIONAL CONSULTATION ON INCONTINENCE - ICI GUIDELINE CHAPTER

IPBF chair Jane Meijlink participated throughout 2021 in the international committee chaired by Professor Philip Hanno on updating the ICI guideline chapter on IC/BPS which will be published in 2022. This included online discussion meetings in January and November.

MEMBERSHIPS

The IPBF is an associate member of the International Alliance of Patients' Organizations (IAPO), World Patient Alliance (WPA), EURORDIS for rare diseases in Europe and Pain Alliance Europe (PAE). The IPBF is also associated with the International Continence Society (ICS), the European Association of Urology (EAU), the International Association for the Study of Pain (IASP) and ESSIC.

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 2021. Many IC/BPS patients worldwide have been very worried about the impact of Covid on their bladder and needed to discuss this with us. Patients have experienced difficulties in getting appointments for diagnostic investigations and treatment due to the pandemic. These problems led to a global exchange of information between patient organisations.

SPECIAL THANKS TO SPONSORS AND DONORS

The IPBF would like to thank its sponsors in 2021. The IPBF is dependent on donations. Funding received in 2021 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.

2021 A SUCCESSFUL AND ACTIVE YEAR

Despite COVID and all the restrictions, 2021 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 2021 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 2021 SUMMARY

Sponsor funding and donations received:	€ 9,100
General operating expenses:	€ 6,954
Information material, IT, website, project and conference/meeting expenses:	€ 5,646

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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