

ANNUAL REPORT OF THE STICHTING INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF) FOR THE YEAR 2020

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 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 2020

IMPACT OF COVID-19

COVID-19 has had a dramatic impact worldwide, presenting multiple challenges for the patient support and advocacy world, including the IPBF. From March onwards, all physical meetings and conferences were cancelled and all communication, contact and learning opportunities moved online. The first aspect about which we were all concerned was whether patients were getting access to treatment in the hospitals and whether sufficient supplies of treatments were available. The impact of the COVID crisis on our IC/BPS has been felt in all countries. Medical and healthcare resources in 2020 were diverted to COVID which took priority over all else in many countries. There were few or no hospital appointments, treatment was often suspended - with a big impact on instillations - and there were long waiting lists for new patients. While telemedicine tried to fill the gap, this did not help patients who needed hospital instillations. However, in countries such as Hungary and the Netherlands, many patients are able to do self-instillation so hospital access has been less of a problem. Like other patients with bladder or bowel urgency disorders, IC/BPS patients were greatly affected by the closure of public toilets during the COVID crisis. This led to even more isolation.

On the other hand, where the patient advocates are concerned, this (first) pandemic year proved to be a great year for virtual communication and education and has shown us a clear potential pathway for the future. In today's virtual world, this is the way not only to raise awareness but also to teach our patient advocates and provide support to our IC/BPS patient support groups worldwide. The many webinars and virtual conferences organised in 2020 were a wonderful learning opportunity for patient advocates, sitting in their own home with their own bathroom and no need to travel, and this possibility ideally needs to continue in the future, even when this COVID-19 crisis is finally over. A positive development is that there has been more virtual contact between the leaders of support groups around the globe than ever before.

VIRTUAL GLOBAL MEETING OF IC/BPS PATIENT ADVOCATES ON 5 DECEMBER 2020, ORGANIZED BY THE DUTCH ICP AND IC INDIA

A virtual meeting on 5 December 2020 organized by the Dutch ICP and IC India. Around 19 patient advocates took part. The aim was to catch up on developments in the different countries, exchange information between the IC/BPS patient associations and obtain feedback on the impact of COVID-19 on the IC/BPS patients. A short presentation was also given by IPBF chair Jane Meijlink on the changing role of patient support groups, stressed that it is now essential to have some kind of global alliance – a central point - where support group leaders can obtain help, advice and up-to-date information, as well as moral support for the support group leaders themselves when they find everything getting too much for them – for example they may get burnout - with the risk of the whole support group collapsing which has happened so often. In addition, as we have seen from these patient advocate meetings, feedback from the different support groups is invaluable since it provides a true picture of the situation at grassroots level. Today far more is expected of support groups than in the past. They may now be required to interact with local and national authorities, sit in working groups or committees with healthcare and pharma professionals, represent the patient perspective in research projects, attend national and even international medical conferences and much more besides. We therefore need to think of education in the more scientific and medical aspects of IC/BPS to prepare patient advocates for the roles they may have to play. A discussion of access to treatment revealed that many patients everywhere are unable to afford treatment. A detailed review of this virtual meeting can be found at: https://www.painful-bladder.org/pdf-2/2020-12_VirtGlobM_Review_Global_Meeting_Patient_Advocates.pdf

ESSIC MASTERCLASS AND ONLINE DISCUSSION WEBINARS

ESSIC is the International Society (originally the European Society) for the Study of Interstitial Cystitis/Bladder Pain Syndrome and associated disorders. Since an annual conference was not possible in 2020, it was decided to hold an online Masterclass of videos on different topics as well as a series of virtual discussion webinars in which the IPBF was represented and gave a presentation.

VIRTUAL ANNUAL MEETING OF THE GLOBAL INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME SOCIETY (GIBS), INDIA, 5 & 6 SEPTEMBER 2020

Virtual meetings and conferences allow far more health professionals and patient advocates to participate than a face-to-face conference. And this 2-day virtual meeting of GIBS, in cooperation with the Urological Society of India (USI), was no exception. With many participants from countries worldwide, it was a global virtual event and an ideal way of educating a maximum number of people, including a large number of patient advocates. Participants were able to submit written questions both in advance and during the meeting online and this led to lively panel discussions. A review is available on the IPBF website: https://www.painful-bladder.org/pdf-2/2020-09_GIBS_India.pdf
GIBS/India also organised numerous educational webinars throughout the year.

OTHER VIRTUAL CONFERENCES

The conferences we usually attend were all moved online in 2020 and the IPBF participated in the virtual conferences of the American Urological Association, the European Association of Urology, the International Continence Society and the International Association for the Study of Pain.

UROWEBINAR: LOCAL INTRAVESICAL INSTILLATION THERAPY OF IC/BPS (PRESENT AND FUTURE)

This webinar on 5 November 2020 was presented by IC/BPS experts Dr Dick Janssen from the Netherlands and Dr Sandor Lovasz from Hungary and organized by the European School of Urology. It is available online, see <https://uroweb.org/education/online-education/webinars/> under Recorded Webinars.

SUCCESSFUL RESEARCH STRATEGIES THE PATIENT COMMUNITY IS USING IN TIMES OF COVID-19

This webinar was organised on Tuesday 23rd June 2020 by Nick Hicks of Commutateur Advocacy Healthcare Communications (www.commutateuronline.com). Jane Meijlink, chair of the IPBF, was invited as panelist and speaker on "How can the new, younger generation of patient advocates be trained up so they can participate more in Pain and Interstitial Cystitis research"

RESEARCH PARTICIPATION

IMI-PAINCARE RESEARCH MEETING

The IPBF is an official participant in the European IMI-PainCare Research Consortium which includes the TRiPP project with its emphasis on research into endometriosis and IC/BPS. 2020 was again a year of intensive work, with the IMI-PainCare General Assembly of all project partners held 15-16 January in the UK and monthly teleconferences throughout the year. The IPBF has also played an active role in preparing journal publications from the research consortium. Further information on IPBF participation in IMI-PainCare: https://www.painful-bladder.org/pdf-2/2020_IMI_PainCare%20Review.pdf and <https://imi-paincare.eu/NEWS/>

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.

INTERNATION CONSULTATION ON INCONTINENCE(ICI) IC/BPS GUIDELINE COMMITTEE

The IPBF Chair was also invited to participate in the international working group for the International Consultation on Incontinence (ICI) guideline for diagnosis and treatment of IC/BPS. Due to COVID, this had to be rescheduled but work has now restarted with online discussions.

SCIENTIFIC PUBLICATIONS

Articles published in 2020 in which the IPBF played an author role are:

- Hanno P, Fall M, Meijlink J, Nordling J. Towards a new paradigm in bladder pain syndrome and interstitial cystitis. *BJU Int.* 2020 Nov;126(5):549-550. doi: 10.1111/bju.15223. Epub 2020 Sep 19. PMID: 32870562.

- Meijlink J. *An urgent case for sensory urgency: A patient perspective.* *Neurourol Urodyn.* 2020 Sep;39(7):2008-2010. doi: 10.1002/nau.24457. Epub 2020 Jul 10. PMID: 32648972.
- Fall M, Nordling J, Cervigni M, Oliveira PD, Fariello J, Hanno P, Kabjörn-Gustafsson C, Logadottir Y, Meijlink J, Moldwin R, Nasta L, Quaghebeur J, Sairanen J, Taneja R, Tomoe H, Ueda T, Wennevik GE, Wyndaele JJ, Zaitcev A. *Comments to Editorial by J. Curtis Nickel. It is premature to categorize Hunner lesion interstitial cystitis as a distinct disease entity.* *Scandinavian Journal of Urology* 2020, Vol. 54, No. 2, 99-100; <https://doi.org/10.1080/21681805.2020.1744714>. *Scand J Urol.* 2020 Aug;54(4):355-356. doi: 10.1080/21681805.2020.1784269. Epub 2020 Jun 26. PMID: 32588705.
- Fall M, Nordling J, Cervigni M, Dinis Oliveira P, Fariello J, Hanno P, Kåbjörn-Gustafsson C, Logadottir Y, Meijlink J, Mishra N, Moldwin R, Nasta L, Quaghebeur J, Ratner V, Sairanen J, Taneja R, Tomoe H, Ueda T, Wennevik G, Whitmore K, Wyndaele JJ, Zaitcev A. *Hunner lesion disease differs in diagnosis, treatment and outcome from bladder pain syndrome: an ESSIC working group report.* *Scand J Urol.* 2020 Apr;54(2):91-98. doi: 10.1080/21681805.2020.1730948. Epub 2020 Feb 28.

AWARENESS AND INFORMATION

In 2020, 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.

During 2020, the IPBF website and other information and educational materials were radically updated. The information and educational materials on the website are NOW produced in the simplest way possible so as to allow easy updating and downloading. In this way patient support groups can use the material on the website and adapt it to their own culture and healthcare system.

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 February, May, August and December 2020 and distributed worldwide by email. [Click here.](#)

CAPACITY BUILDING

On request, the IPBF also helps new (local) patient support groups get started. In 2020, 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.

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 2020, the IPBF particularly emphasized the lack of reimbursement of treatment and the consequent unaffordability of essential treatment.

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 we are very grateful for all the help and advice they provided during 2020.

PROBLEM AREAS

There is still a considerable problem concerning terminology and definitions, with several different names being used, leading to devastating reimbursement issues for patients in many countries. Many patients are unable to have the essential treatment they need because they simply cannot afford it. This is also partly due to lack of scientific evidence due to inadequately designed studies and failure to phenotype/subtype.

SPECIAL THANKS TO SPONSORS AND DONORS

The IPBF would like to thank its sponsors in 2020. The IPBF is dependent on donations. Funding received in 2020 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.

2020 A SUCCESSFUL AND ACTIVE YEAR

Despite COVID and all the restrictions, 2020 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.

The chairman would like to thank all IPBF board members for their hard work, help, advice and input during the year 2020 and to thank all IC 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 2020 SUMMARY

Sponsor funding and donations received:	€ 11,205.51
General operating expenses:	€ 5,139.57
Information material, IT, website, project and conference/meeting expenses:	€ 8,443.34

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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