

International Painful Bladder Foundation

The IPBF is a voluntary non-profit organization focused on interstitial cystitis/bladder pain syndrome/hypersensitive bladder/Hunner lesion
www.painful-bladder.org

IPBF e-Newsletter

Issue 61, February 2022

An IPBF update for patient support groups, healthcare professionals and friends around the world in the field of interstitial cystitis, bladder pain syndrome/painful bladder syndrome, hypersensitive bladder, Hunner lesion, ketamine cystitis, chronic pelvic pain and associated disorders.

This issue of the IPBF e-Newsletter includes the following topics:

- General Update
- ESSIC Focusing Webinars
- ESSIC Annual Congress 2022
- 3rd virtual Global IC/BPS Patient Advocates Meeting
- ICD-11 officially launched
- Europe: IMI changed to IHI
- IMI-PainCare Update
- IPBF Presentations
- Patient Engagement
- New books/publications
- COVID-19: Information About COVID-19 And Useful Online Resources
- Overview of upcoming events
- Donations & Sponsoring

GENERAL UPDATE

Covid-19 continues, leading to continued restrictions with regards to meetings and conferences. The latest casualty is the European Association of Urology EAU 2022 congress in Amsterdam, planned for March but now postponed due to the announcement of Dutch government regulations for meetings. A new date will be announced in the coming period.

A reminder: anyone planning to attend in-person conferences must check well in advance what health requirements/regulations may be in force (e.g. vaccination and test certificates), bearing in mind that these regulations can change by the day.

- Online Educational Webinars Reveal Areas of Confusion

In the past months, we have seen dedicated educational webinars on diagnosis and treatment from GIBS in India in cooperation with surrounding countries, a masterclass and the first in a series of focused webinars from ESSIC and presentations on IC/BPS in several webinars on functional urology. All of these once again reveal the confusion regarding the name of this disease! It would therefore be useful if a determined effort could be made in 2022 to achieve international consensus in 1) terminology and definitions and 2) in clinical guidelines. The current terminology confusion, differing definitions of that terminology, and different priorities in guidelines (e.g. at what stage do you perform a cystoscopy) do not help clinicians around the world to diagnose and treat their patients. This particularly applies to clinicians who may have just one or two IC/BPS patients, are not experienced in this field and therefore need the basic information which they require in their clinical practice to specifically treat IC/BPS patients to be clearly and concisely laid out. Furthermore, newly diagnosed

patients are very confused and uncertain when they discover that their disease has multiple names and quite rightly wonder whether it is being taken seriously.

- Research

Despite the Covid-19 pandemic, scientific research has continued with a record number of studies published on all aspects of IC/BPS and comorbidities (PubMed) in 2021. As you can see from the **IPBF Research Update** which is now online as a separate pdf file, research into IC/BPS is being carried out worldwide, with many studies taking place in East Asia. This steadily increasing global spread is welcome news.

ESSIC FOCUSING WEBINARS

- WEBINAR 2: BEHAVIOURAL MANAGEMENT & DIET - 18 FEBRUARY 2022 – TIME: 14.00 CET REGISTRATION FREE OF CHARGE - SCIENTIFIC DIRECTORS: JJ WYNDAELE & ROBERT MOLDWIN

This will be the second of a series of webinars organised by ESSIC (International Society for the Study of IC/BPS) as a new approach to science, research and especially optimal management of IC/BPS in today's world. Each webinar focuses on a specific topic. The previous one dealt with Physiotherapy. This webinar deals with behavioural management and diet, a very important part of therapy for all IC/BPS patients.

It will be presented by top specialists in the field, all with immense knowledge and experience in the practical, clinical field of application. Speakers in this second webinar will be: Dick Janssen (Netherlands), Barbara Gordon (USA), Robert Moldwin (USA) and Jean-Jacques Wyndaele (Belgium). Details can be found at <https://www.essic.org/copy-of-essic-focussing-webinars> where you will also be able to register as a participant. Contact for queries: info@essic.org.

ESSIC ANNUAL IC/BPS CONGRESS 2022, NICE, FRANCE, SAVE THE DATE!

The ESSIC 2022 annual congress on IC/BPS will take place on 2-4 December 2022 in Nice, France. Reduced fees will be available for ESSIC members. Further details regarding the preliminary scientific programme and faculty will be available soon on the ESSIC website: <https://www.essic.org/>.

3rd VIRTUAL GLOBAL IC/BPS PATIENT ADVOCATES MEETING HELD 11 DECEMBER

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. Some of the key topics were as follows: the Italian patient group AICI has made a short film to raise awareness about IC/BPS. They also stressed the urgent need for the creation of an IC/BPS Biobank and suggested that a road map of all IC/BPS products available in each country could be drawn up. Therapies are not available in all countries and the goal is to make them available – and affordable – everywhere. Elmiron (oral PPS) and the potential for eye damage was discussed, it was also asked whether it is safe for pregnant women and whether PPS is safer as an instillation rather than an oral drug. IC India emphasised that healthcare for patients was totally disrupted by particularly the second wave of Covid-19, infection with Covid appeared to exacerbate bladder inflammation of many IC/BPS patients and this continued for many months after recovery from the infection. Many patients were left with post-Covid fatigue symptoms. This was also emphasised by the Israeli patient group. In Israel they are making a big effort to try to get bladder instillations reimbursed. The non-reimbursement of instillations is an issue affecting many countries. In the UK, Covid had caused extremely long waiting lists for new patients to receive investigations. This was the same in Denmark. In Hungary, patients able to do self-instillation at home were able to cope well despite the pandemic. The Spanish ACACI had been organising virtual support meetings via Zoom and participated in a public toilets national campaign. The lack of public toilets is an issue in most countries and has been even worse during the pandemic. In France, they have no specific guideline for IC/BPS and there is still insufficient awareness

of IC/BPS in the medical community, this makes the patient journey still long and discouraging. Lack of awareness at primary care level means long delays in referral. A USA presentation looking at treatment options emphasised that multimodal treatment may be the best for many patients. In the Netherlands, the GETSBI study into bladder instillations has started and the ICP is working on a refresher course project for general practitioners (primary care) which is greatly needed. Everyone emphasised the need for more treatment-related research and studies since many patients are still not receiving adequate treatment and some none at all; also studies aimed at easing the non-reimbursement of treatment situation while many patients wish to see more studies into the root cause(s).

INTERNATIONAL CLASSIFICATION OF DISEASES-11 (ICD-11) NOW OFFICIALLY LAUNCHED

The International Classification of Diseases-11 (ICD-11) came into effect on 1 January 2022. The ICD is maintained by the World Health Organization (WHO) and distributed in countries across the globe. An ICD code is assigned to every disease. Coding has many practical implications. The codes ensure that you get proper treatment and are charged correctly for any medical services you receive. Insurance companies expect the codes to be consistent between a condition and the treatment rendered. The codes are followed in clinical trials to recruit and track subjects. ICD codes are also used globally to track health statistics such as morbidity (ill health) and mortality (causes of death). While ICD-11 officially came into effect on 1 January 2022, each country chooses when to adopt it, and the WHO recognises that few countries are likely to adopt the new ICD-11 coding at the time of its launch. The coding system can be found at: <https://icd.who.int/en>

You can then select the ICD-11 browser to see content: <https://icd.who.int/browse11/l-m/en>

You can explore by typing a term in the search box. Try “interstitial cystitis”, for example. You will find this under GC00.3 Interstitial cystitis which falls under Diseases of the genitourinary system. So far, so good, this part is understandable. However, you will also find a reference to MG30.00 Chronic primary visceral pain which includes chronic primary bladder pain syndrome. This is not entirely clear and some of the terminology does not tally as in one place they use bladder pain syndrome and in another painful bladder syndrome/interstitial cystitis, even though the current global trend is interstitial cystitis/bladder pain syndrome. This may prove to be an example of “too many cooks spoil the broth”!!

EUROPE: INNOVATIVE MEDICINES INITIATIVE (IMI) HAS BEEN CHANGED TO THE INNOVATIVE HEALTH INITIATIVE (IHI)

The Innovative Medicines Initiative (IMI) started life in 2008 as a public-private partnership (PPP) between the European Union and the European pharmaceutical industry. The initiative proved successful, and in 2014 the IMI2 programme was launched. The IMI1 and IMI2 programmes resulted in almost 200 projects covering a wide range of disease areas and addressing challenges across all areas of medical research and drug development. These included the ongoing IMI-PainCare research consortium which is researching IC/BPS and endometriosis in its TRiPP project.

The new Innovative Health Initiative (IHI) will build on the successes of the Innovative Medicines Initiative (IMI). It will still be a European public-private partnership dedicated to advancing health research and innovation, but working across a broader range of sectors, with new partners and an updated governance structure. In the meantime, it will keep supporting the projects launched under IMI. From a legal point of view, the legislation creating IHI replaces the legislation creating IMI. This means that the IHI Programme Office will continue to manage the IMI projects, many of which still have years to run.

The IHI was launched at an online event on 26 January 2022. The event was a great success with 2,400 participants representing different IHI stakeholders from academia, industry, small and medium enterprises, research bodies and of course patients, with the IPBF also participating. For those unable to attend the live event, the recording and presentation are now available. Click here for the [recording](#) and [presentation](#).

Further information about IHI can be found at: <https://www.ihl.europa.eu/about-ihl/imi-ihl>

IMI-PAINCARE RESEARCH CONSORTIUM: IPBF PARTICIPATION UPDATE

Following the launch of IHI, the IMI-PainCare Consortium project – like all other IMI research projects already in progress at the time of the switch to IHI - will continue under the same IMI-PainCare name. Three patient advocates have been participating throughout - Judy Birch (chronic pelvic pain), Lone Hummelshoj (endometriosis) and Jane Meijlink (IC/BPS) - who have particularly been involved in the TRiPP part of the project which aims at improving the translation of laboratory and clinically findings into treatment. This has so far proved to be a very successful form of patient participation.

A recent publication from this research group 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

More detailed information about this extensive project can be found at: <https://www.imi-paincare.eu/>

IPBF PRESENTATIONS

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

IPBF Chair Jane Meijlink was invited to give a video presentation of 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 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?

PATIENT ENGAGEMENT

Patient engagement is the involvement of - and consultation with - patients and their associations in research and other projects. This can help researchers on the one hand to find out what kind of treatment patients need and want, and on the other hand gain insight into potential sub-groups or phenotypes of patients. Diseases and disorders of which the cause is as yet unknown tend to give rise to multiple theories which then start to lead a life of their own. Involvement of patient associations in for example research consortia or guideline projects can help keep the focus on the practical realities – the real symptoms in the real patients - rather than on unproven theories. Patient associations are today a goldmine of information but are still not being fully utilised.

However, in order to achieve high quality patient engagement, patient organisations need to ensure that they have patient representatives with a good knowledge of the medical aspects of IC/BPS, from diagnosis, treatment and psychosocial aspects to guidelines and standard terminology and definitions. In the past, this was achieved by sending patient representatives to professional conferences and symposia. The first generation of patient representatives were spoilt for choice with a series of NIDDK internationally attended symposia on interstitial cystitis, IC symposia in Europe organised by ICA-

Deutschland, international ICICJ conferences in Japan and regular ESSIC IC/BPS conferences. Patient representatives could also be seen at urology conferences including AUA, EAU, ICS etc. as well as IASP pain conferences, often with an info stand in the exhibition.

However, as already mentioned, in recent years there have been far fewer dedicated IC/BPS conferences and therefore many of these learning opportunities became few and far between. In the last two years, the Covid-19 pandemic has led to the cancellation of most in-person conferences. On the other hand, we have seen a proliferation of online virtual conferences and educational webinars, ideal for those who find it difficult or too expensive to travel. What we have missed, however, has been face-to-face discussion, the opportunity to comment or ask questions and of course the networking.

Since patient engagement in research is now often a requirement rather than an option, we now need to think seriously about how best to educate our upcoming generations of patient representatives/advocates to ensure that they have a broad knowledge of – specifically - all aspects of IC/BPS and its comorbidities so as to be able to participate to a maximum in research projects and guidelines. Educational webinars and online material may be an answer.

NEW BOOKS/PUBLICATIONS

THE INTERNATIONAL SOCIETY FOR THE STUDY OF VULVOVAGINAL DISEASE (ISSVD): PATIENT HANDOUTS AND PODCASTS

While many IC/BPS patients suffer from vaginal disorders, it is not always easy to find reliable information. The International Society for the Study of Vulvovaginal Disease (ISSVD - <https://www.issvd.org/>) has designed a complete section on its website with patient handouts on the most important topics related to vulvovaginal diseases, offering open access to the latest information and insights. These can be accessed via: <https://www.issvd.org/publications/patient-handouts>.

ISSVD publications also include a series of very interesting podcasts:

<https://www.issvd.org/publications/podcasts>

A visit to the ISSVD website is a “must” for both health professionals and patient organisations.

CLINICAL & EXPERIMENTAL RHEUMATOLOGY: FOURTH ANNUAL SUPPLEMENT ON SJÖGREN'S SYNDROME 2021 VOL.39, N°6 - SUPPL.133

Guest Editors: M. Bombardieri, H. Bootsma, S. De Vita, T. Dörner, M. Ramos-Casals, A.G. Tzioufas

Open access. <https://www.clinexprheumatol.org/a.asp?IDArchivio=255>

“Sjögren’s syndrome (SS) is a multifactorial systemic autoimmune disease of unknown aetiology characterised by a wide spectrum of different clinical manifestations and scattered complications”. This extensive annual review 2021 summarises the main scientific developments in the previous year. It is open access and therefore available to all.

However, in recent years there appears to have been a lack of interest in the effects of Sjögren’s on the urinary bladder - particularly by rheumatologists - despite the fact that there are patients around the world with a combination of Sjögren’s and IC/BPS or hypersensitive bladder. We urgently need to see renewed action here since research could throw more light on this phenotype and aid better treatment.

STATPEARLS FREE BOOKS & DOCUMENTS: KETAMINE TOXICITY

Vwaire J. Orhurhu, Rishik Vashisht, Lauren E. Claus, Steven P. Cohen. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan. PMID: 31082131 Bookshelf ID: NBK541087

<https://www.ncbi.nlm.nih.gov/books/NBK541087/>

Ketamine toxicity can cause a variety of neurological, cardiovascular, psychiatric, urogenital, and abdominal symptoms, which are dose-dependent, and depend on whether ketamine administration was in an iatrogenic or illicit context. For example, some experts have attributed the higher incidence of ulcerative cystitis in recreational users to the adulterants with which the drug is mixed. Emergency medicine providers should be aware of the various mechanisms to treat ketamine toxicity and to prevent acute complications such as rhabdomyolysis, seizures and chronic complications such as psychiatric disturbances and ulcerative cystitis.

COVID-19: INFORMATION ABOUT COVID-19 AND USEFUL ONLINE RESOURCES

- The International Alliance of Patients' Organizations (IAPO) has put together a useful COVID-19 resources hub at <https://www.iapo.org.uk/covid-19-resources-hub>.
- FDA- US Food & Drug Administration: <https://www.fda.gov/patients/coronavirus-disease-2019-covid-19-resources-patients>, <https://www.fda.gov/health-professionals/coronavirus-disease-2019-covid-19-resources-health-professionals>
- Harvard Medical School: <https://www.health.harvard.edu/diseases-and-conditions/covid-19-basics>
- National Institutes of Health (NIH):
<https://www.coronavirus.gov/>
<https://covid19.nih.gov/>
<https://combatcovid.hhs.gov/>
- United Kingdom National Health Service (NHS):
<https://www.nhs.uk/conditions/coronavirus-covid-19/>
- WHO Coronavirus disease (COVID-19) <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>
- CDC (Centers for Disease Control and Prevention): Things to Know about the COVID-19 Pandemic.
<https://www.cdc.gov/coronavirus/2019-ncov/your-health/need-to-know.html>
- CDC (Centers for Disease Control and Prevention), USA: symptoms of coronavirus
<https://www.cdc.gov/coronavirus/2019-ncov/symptoms-testing/symptoms.html>
- CDC (Centers for Disease Control and Prevention), USA: risk of reinfection
<https://www.cdc.gov/coronavirus/2019-ncov/your-health/reinfection.html>
- European Medicines Agency (EMA)
<https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19#what's-new-section>
<https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines-covid-19>
- IASP: Long Hauler COVID-19 Pain Morbidities and Their Management: <https://www.iasp-pain.org/education/part-2-long-hauler-covid-19-pain-morbidities-and-their-management/>
- For speakers of Dutch, Dr Joop P. van de Merwe in the Netherlands is continually updating a highly informative, well-documented overview of all aspects of COVID-19 (in Dutch). The introductory page with a link to the overview can be found at: <https://www.jpvandemerwe.nl/corona> The overview itself can be accessed directly at <https://www.jpvandemerwe.nl/corona/pdf/coronapaper.pdf>, scroll down the page to access the book.

OVERVIEW OF UPCOMING EVENTS (PLEASE CHECK RELEVANT WEBSITES FOR UPDATES)

Please note that in the case of **in-person meetings**, proof of vaccination and a COVID-19 negative PCR or antigen test result may be required during check-in at the meeting. Please check health requirements and regulations in advance.

ESSIC FOCUSING WEBINARS: WEBINAR 2: BEHAVIOURAL MANAGEMENT & DIET

18 February 2022 – Time: 14.00 CET – Registration Free of Charge

Scientific Directors: JJ Wyndaele & Robert Moldwin

Registration and info: <https://www.essic.org/copy-of-essic-focussing-webinars>

Contact for queries: info@essic.org.

SOCIETY OF URODYNAMICS, FEMALE PELVIC MEDICINE AND UROGENITAL RECONSTRUCTION (SUFU) - SUFU22 WINTER MEETING

22-26 February 2022, Marriott Marquis San Diego Marina, San Diego, CA, USA.

SUFU is offering both **virtual and in-person registration options** for the 2022 Meeting.

<https://sufuorg.com/meetings/upcoming-sufu/meeting-information.aspx>

37TH ANNUAL EAU CONGRESS (EAU22)

The European Association of Urology annual congress planned for March in Amsterdam has been postponed due to Covid-19 regulations in the Netherlands. A new date will be announced in the coming month. Please check the EAU website for updates: <https://eaucongress.uroweb.org/>

12TH CONGRESS OF THE EUROPEAN PAIN FEDERATION (EFIC)

27-30 April 2022, Dublin, Ireland.

<https://efic-congress.org/>

<https://efic-congress.org/health-and-safety/>

AMERICAN UROLOGICAL ASSOCIATION (AUA 22)

13-16 May 2022, New Orleans Ernest N. Morial Convention Center

900 Convention Center Boulevard, New Orleans, LA 70130, USA

<https://www.auanet.org/annualmeeting>

<https://www.auanet.org/annualmeeting/health-and-safety>

EUROPEAN ALLIANCE OF ASSOCIATIONS FOR RHEUMATOLOGY – EULAR22

1-4 June 2022, Copenhagen, Denmark. A hybrid conference: the EULAR 2022 European Congress of Rheumatology will be held both virtually through the Congress platform and on-site in Copenhagen at: Bella Center Copenhagen, Center Boulevard 5, DK - 2300 Copenhagen

<https://congress.eular.org/>

THE INTERNATIONAL SOCIETY FOR THE STUDY OF VULVOVAGINAL DISEASE - ISSVD XXVI WORLD CONGRESS

18-20 July, 2022 Trinity Business School Trinity College, Dargan Auditorium, Dublin, Ireland

(Preceded July 15 & 16, 2022 by International Vulvovaginal Disease Update 2021:)

<https://www.issvd.org/events>

INTERNATIONAL CONTINENCE SOCIETY (ICS) ANNUAL MEETING 2022

7-10 September 2022, Vienna, Austria. Meeting Venue: Austria Centre Vienna

<https://www.ics.org/2022>

**INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN (IASP)
WORLD CONGRESS ON PAIN**

19-23 September 2022, Metro Toronto Convention Centre, Toronto, Canada.

<https://iaspworldcongress2022.org/>

ESSIC 2022 ANNUAL CONGRESS ON IC/BPS

2-4 December 2022 in Nice, France. Reduced fees will be available for ESSIC members. Further details regarding the preliminary scientific programme and faculty will be available soon on the ESSIC website: <https://www.essic.org/>.

DONATIONS AND SPONSORING – THE IPBF NEEDS FINANCIAL SUPPORT TO CONTINUE ITS INTERNATIONAL PATIENT ADVOCACY AND AWARENESS CAMPAIGN AROUND THE GLOBE.

The voluntary, non-profit IPBF is entirely dependent on sponsoring and donations to be able to continue to carry out its international advocacy, projects and newsletters. In these difficult economic times, it is not easy for us to keep going and ensure continuity. All donations to our international work, however small, will be most gratefully received. The IPBF has fiscal charity status in the Netherlands. If you are thinking of making a donation, please go to this link for bank details: http://www.painful-bladder.org/donations_sponsoring.html

We would like to take this opportunity of thanking our donors for their greatly appreciated support in the past year for our foundation, projects, patient advocacy, website and newsletters.

THE BOARD - INTERNATIONAL PAINFUL BLADDER FOUNDATION (IPBF)

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, patient information 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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