

# International Painful Bladder Foundation

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

## IPBF e-Newsletter Issue 66, February 2024

*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:

- IPBF Website
- IPBF Research Update link
- Webinars
- Conferences & Meetings 2024
- Current IC/BPS situation: an update
- Role of patients in helping to achieve right diagnosis
- Donations & Sponsoring

### IPBF WEBSITE

Our longtime webmaster Dr Joop P. van de Merwe has stepped down due to health reasons. We would like to thank him for the huge amount of work he did for the IPBF website over the past 20 years. We are immensely grateful for all his work and support and send him our best wishes.

The IPBF website is currently undergoing a software update, so you may find that some items have been moved to a different place.

### IPBF RESEARCH UPDATE ONLINE LINK

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

In our IPBF Research Update, we endeavour to indicate per abstract which country or countries have been involved in the presented research. This gives everyone a clear idea of who is doing what in which part of the world.

Patient advocates and their organizations who wish to learn more about scientific developments will find the Open Access papers very useful. This is important to equip them better for patient participation in research projects or patient advisory panels and of course to help educate the members of their support groups and train the younger generation of potential advocates.

### WEBINARS

Webinars for the education of both patients/patient advocates and health professionals are springing up everywhere worldwide. This has in part been a valuable spin-off from Covid and

lockdown. It is now realized that not everyone has the means or time to travel to conferences around the world and a much wider audience can be reached via the internet. Many conferences are hybrid (live and online) or it is possible to follow recordings online after the event.

In addition, many societies – both patient and medical – are organizing educational courses. Some of these are free, some with payment and some only free to members.

Check out AUA, EAU, ICS, IASP, IUGA, eUrogen, GIBS, and many national societies.

### **ICA WEBINARS**

Specifically for patient education (but useful for health professionals too), the Interstitial Cystitis Association (ICA <https://www.ichelp.org/>) has been organizing an excellent series of webinars on Navigating IC/BPS: Conversations with Experts. Check these out at <https://ichelp.org/navigatingicbps>. They are excellent for capacity building as well as general knowledge of all aspects of IC/BPS.

On 27 March 2024, there will be a webinar in the monthly series entitled “Understanding the Different Subtypes or Phenotypes of IC/BPS”. Speaker Jill Peters-Gee MD. Further information about registration: [click here](#).

### **ERN eUROGEN (<https://eurogen-ern.eu/>)**

European Reference Networks (ERNs) are virtual networks connecting healthcare providers (HCPs), professionals, and patients across the EU/EEA and aim to tackle rare diseases and complex conditions requiring highly specialised treatment by pooling knowledge and resources and thereby improving diagnoses and treatment for patients.

ERN eUROGEN is the European Reference Network (ERN) for rare urogenital diseases and complex conditions and includes interstitial cystitis, with a series of webinars in cooperation with ESSIC.

The eUrogen webinar programme can be seen at <https://eurogen-ern.eu/webinars/webinar-programme/>

Past webinars available on YouTube can be found at <https://eurogen-ern.eu/webinars/past-webinars/> See under EA 2.5 Interstitial Cystitis.

## **CONFERENCES AND MEETINGS 2024**

### **JOINT 5<sup>TH</sup> ICICJ AND ESSIC 2024, KYOTO, JAPAN 21-23 AUGUST 2024**

A highlight of this year for the IC/BPS world will undoubtedly be the meeting to be held in Kyoto, Japan entirely devoted to IC/BPS. This will be the Fifth International Consultation on Interstitial Cystitis, Japan (ICICJ) and will be held jointly with the Annual Meeting of the International Society for the Study of Bladder Pain Syndrome (ESSIC) 2024. It will take place from Wednesday 21 August to Friday 23 August 2024.

Further information concerning this exciting upcoming conference will be available in the coming months. In the meantime, reserve the date in your calendar!

For the younger generation, it may be interesting to say something about the history of ICICJ meetings in Kyoto. The very first ICICJ meeting was organised 21 years ago in 2003 by Dr Tomohiro Ueda in the beautiful historic city of Kyoto. It was a unique and memorable international gathering of experts from many different countries, attended by both doctors and patient advocates. At that time there was no global consensus on the nature of the

disease, the definition was unclear and there was no international clinical guideline. Many patients were not getting a diagnosis and in many countries it was even claimed that IC did not exist in their country!

The first ICICJ with its workshops and discussion groups revealed the extent of the gaps. A start was made on obtaining global consensus on the disease. At the second ICICJ in 2007, group discussions were held on terminology, definitions, diagnosis, and evaluation, attended by participants from all over the world including the Asia-Pacific Rim, Americas, and European regions. At the third ICICJ in 2013, two new sessions were organised with the theme of "Expression & classification based on pathophysiology". At the fourth ICICJ (2018), consensus was reached that bladder pain syndrome and Hunner Lesion are separate entities requiring different treatment approaches. However, the diagnosis of Hunner Lesions depends on cystoscopy which is not compulsory in the United States for example.

It is hoped that the upcoming 5th ICICJ conference this year will be of value not only for clinicians involved in patient management but also for those involved in developing new treatment modalities and those planning research in the future. A main theme of the meeting will be "Diagnostic support using AI-based machine learning algorithms (AINAFHIC) in cystoscopic evaluation of Hunner lesions".

#### **[EAU 2024 – 39<sup>th</sup> ANNUAL CONGRESS OF THE EUROPEAN ASSOCIATION OF UROLOGY](#)**

5-8 April 2024, Venue: Expo Porte de Versailles, 75015 Paris, France.

The EAU 2024 congress includes a **Patient Day**, organised by the EAU Patient Office, on Friday 5 April from 09.00 to 15.45 hrs, Room W08 Green Area, which offers a platform where healthcare professionals (HCPs) and patient advocates can meet to share perspectives and experiences. Further information: <https://eau24.org/patient-day>

The Patient Day programme will start at 09.00 with the Patient Abstract session.

The session themes include **Roundtable #3: Inflammatory Bladder** to be held at 13:30 - 14:30 in the Green Area W08 and will be chaired by Dr Dick Janssen and Jane Meijlink. This session will focus on three inflammatory bladder conditions: Interstitial Cystitis/Bladder Pain Syndrome, chronic radiation-induced cystitis and ketamine-induced cystitis.

In addition to the EAU24 Patient Day, there will be patient-centred sessions included in the EAU24 scientific programme. You can improve your digital communication skills in the Hands-on Training course ChatGPT for Beginners, designed in a collaboration between the Patient Office and ESU. Or you can connect directly with patient advocates over a coffee in the Patient Lounge (D80).

Patient advocates can register for the congress for free and are eligible to apply for a €500 travel grant. A letter is required stating why you want to attend the congress and you must agree to submit a post-congress report, describing your congress experience and areas for improvement. Applications are accepted on a first-come-first-serve-basis. To apply send an email to [info.patientinformation@uroweb.org](mailto:info.patientinformation@uroweb.org) or go to

<https://eaucongress.uroweb.org/registration/delegate-fees/>

Proof of status for non-members is required: A written confirmation in English from the associated patient advocacy group confirming your membership, no older than 3 months. Patient Advocacy groups are eligible to apply for a complimentary desk in the Exhibition area.

### **AMERICAN UROLOGICAL ASSOCIATION - AUA 2024**

3-6 May 2024, San Antonio, USA

The AUA 2024 annual meeting includes the following of specific interest in our field:

#### **Poster and Podium Session**

PD25: Infections/Inflammation/Cystic Disease of the Genitourinary Tract: Interstitial Cystitis  
Saturday, May 4, 2024 9:30 AM to 11:30 AM · 2 hr. (America/Chicago)

#### **Instructional Course**

049IC - Emerging Concepts in Interstitial Cystitis/Bladder Pain Syndrome, Sunday, May 5, 2024 7:30 AM to 9:30 AM · 2 hr. (America/Chicago)

#### **Instructional Course**

023IC - Surgical Interventions for Pelvic Pain and What to do with Everyone Else  
Friday, May 3, 2024 4:00 PM to 6:00 PM · 2 hr. (America/Chicago)

### **IASP 2024 WORLD CONGRESS ON PAIN**

This congress is organised by the International Association for the Study of Pain (IASP) during IASP's 50th Anniversary year.

5-9 August 2024, Amsterdam RAI, Amsterdam, Netherlands

<https://www.iasp-pain.org>

### **GIBS 2024 - 9<sup>TH</sup> ANNUAL CONGRESS ON IC/BPS**

24-25 August 2024, New Delhi

Theme: "Containing the Bladder Blaze"

Abstract submission closes 31 May 2024

### **ICS 2024 – 54<sup>th</sup> MEETING OF THE INTERNATIONAL CONTINENCE SOCIETY**

23-25 October, IFEMA, Madrid, Spain

Abstract submission closes 3 April 2024 23:59 BST (GMT +1 hr)

ICS invites Clinical and Non-Clinical Abstracts in Urology, Urogynecology, Colorectal, Bowel Dysfunction, Nursing, Physiotherapy, Conservative Management and Pure and Applied Science <https://www.ics.org/2024/abstracts>

### **CONFERENCES ON COMORBID CONDITIONS**

#### **16TH INTERNATIONAL SYMPOSIUM FOR SJÖGREN'S DISEASE**

For those interested in Sjögren's, the 16th International Symposium for Sjögren's Disease will take place at Egmond aan Zee, the Netherlands, on 22-25 April 2024. Sjögren's Disease-focused clinicians, scientists and patient organisations are invited to attend.

#### **EULAR EUROPEAN CONGRESS OF RHEUMATOLOGY**

12-15 June 2024 at the Messe Wien Congress Center, Vienna, Austria.

Since its introduction in 2000, the EULAR European Congress of Rheumatology has become the primary platform for exchange of scientific and clinical information in Europe. It is also a renowned forum for interaction between medical doctors, scientists, people with arthritis/rheumatism, health professionals and representatives of the pharmaceutical industry worldwide. EULAR provides excellent background information for the rheumatic comorbidities of IC/BPS.

## CURRENT IC/BPS SITUATION: AN UPDATE

### - Still no consensus

While awareness of IC/BPS has hugely improved worldwide in the past 20 years, there is still no global consensus on definitions, evaluation methods or even what the disease actually is. Definitions appear to have become so loosely worded that many patients are being diagnosed with IC/BPS when they may in fact have some other nearby disorder which may be sensitising the urinary bladder or may have pain caused by damage from previous surgery in the pelvic floor and/or in organs neighbouring the bladder.

It goes without saying that no treatment intended for IC/BPS is likely to work in misdiagnosed patients who consequently get more and more desperate by the day. It is therefore vital now to make every effort to achieve the right diagnosis in the right patient, hopefully then leading to the right treatment. However, this takes time, resources and money, all of which are in short supply in today's world and getting shorter by the year. It also takes expertise which is often not always at hand for rare, less common and complex diseases. And IC/BPS certainly features among the complex diseases!

### - Confusing Terminology

Ever since Interstitial Cystitis first appeared in the medical textbooks, terminology has been confused and confusing. However, in an era of electronic medical records and databanks, multiple different names for approximately the same condition leads to chaos for patients, providers, insurance companies, health authorities and – importantly – researchers.

Currently we are faced with the following:

Interstitial cystitis

Chronic interstitial cystitis

Bladder pain syndrome

Painful bladder syndrome

Hypersensitive bladder

Chronic primary bladder pain syndrome

Primary bladder pain syndrome

Hunner Lesion

Hunner's ulcer

Hunner Lesion Disease

Ulcerative interstitial cystitis

Classic IC

IC, PBS, BPS, IC/PBS, PBS/IC, IC/BPS, BPS/IC, HSB, non-HL, HL, HU, HLD, CPBPS, PBPS....

**It is time for everyone involved in IC/BPS to sit round a table – together with patient advocates and their organisations - and try to agree on a name! Please!**

### - ESSIC clinical guideline

ESSIC (the International Society for the Study of IC/BPS) is currently working on the development of a new clinical guideline with an international team from different parts of the world. A major challenge!

## ROLE OF PATIENTS IN HELPING TO ACHIEVE THE RIGHT DIAGNOSIS

Patients themselves can play an important role in helping to obtain the right diagnosis by keeping a detailed record of their medical history, any prior surgery, and exactly when the bladder pain/discomfort and urinary symptoms started. People mistakenly believe that this will all be in the computer somewhere and that information is electronically exchanged between hospitals and doctors by just pressing a button. This is usually not the case and particularly today when people move from hospital to hospital, city to city and country to country with their medical information often in a different language. A clear record of a patient's medical history – and where relevant family medical history - will help to provide a meaningful background for diagnosis and help avoid misunderstandings.

## DONATIONS AND SPONSORING

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

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.*

*If you do not wish to receive this IPBF e-newsletter or any other communications from the IPBF in future, please notify the International Painful Bladder Foundation: [info@painful-bladder.org](mailto:info@painful-bladder.org) with "unsubscribe" in the subject bar.*