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 62, May 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

While everyone everywhere is endeavouring to get their life back after more than 2 years of Covid, no-one should be lulled into thinking that Covid has gone away completely. Due care and caution are still needed in our daily lives. While many conferences are now being organized in-person, we have received reports of attendees arriving back home infected with Covid.

With all of us now fully accustomed to meetings and webinars online, there are so many webinars being organized that it is becoming increasingly difficult to pick and choose which are the most essential, when you are faced with several at the same time on the same day! With "patient engagement" now a focus of attention, organizations are springing up everywhere and naturally also organizing webinars. Perhaps some of these organizations could consider cooperating so as to reduce the number of online meetings and the time required. This would also increase the potential impact of their work.

International webinars in the field of IC/BPS have revealed just how dependent many countries are on the guidelines produced by leading societies. This is precisely why we are devoting space in this IPBF eNewsletter on reviewing various aspects of the updated 2022 guidelines, particularly from a patient perspective. Hopefully this will also encourage others to come forward with comments and suggestions for improvement.

RESEARCH UPDATE NOW IN A SEPARATE PDF ONLINE

In order to facilitate downloading of the Research Update, please note we have now placed the eNewsletter and Research Update in separate pdf files online. Both can be accessed via the IPBF home page. https://www.painful-bladder.org/

BRIEF IPBF REVIEWS OF 2022 GUIDELINE UPDATES – EAU and AUA

The last few months have seen the publication of Guideline updates which have generated some discussion and not a little confusion amongst busy clinicians, researchers and the patient advocacy world. The two guidelines currently under review are the European Association of Urology (EAU)

Guidelines for Chronic Pelvic Pain and the American Urological Association (AUA) Guideline for the Diagnosis and Treatment of IC/BPS.
In many parts of the world – excluding the USA which takes a different approach – IC/BPS is classified as a rare disease, when correctly diagnosed by excluding every other possibility (confusable diseases) by means of cystoscopy and other investigations. This means that the average urologist or urogynaecologist in a general hospital is not going to have too many patients with this condition. Since Covid, clinicians have been busier than ever and therefore have no time to wade through vast tracts of Guidelines to find out exactly what they need to do for just 1 patient in their practice.
Guidelines used internationally for diagnosis and treatment need to be crystal clear, concise, and in plain English, so that any clinician anywhere in the world can immediately see and understand what needs to be done. And let's not forget the patient organisations and their representatives, since they also need to be able to have a clear overview and understanding of each guideline. Researchers too are currently confused about different guidelines with conflicting views and recommendations and different terminology. Yet we rely on these researchers to develop treatment for our patients. It is therefore essential to provide a realistic picture of the (often complex) patient population, using standard terminology and definitions, standard investigations with treatment adjustable to phenotype. It should also by now be clear to everyone that Hunner lesion patients should be treated and researched separately from non-Hunner lesion patients.
Another aspect is that guidelines used internationally could perhaps take account of limited resources in developing countries and provide alternative suggestions to suit the local pocket. This could be a valuable contribution to the developing world.
Below is a brief IPBF look at just a few points in the two guidelines.

- EAU GUIDELINES ON CHRONIC PELVIC PAIN 2022

For the guideline introductory page, go to: https://uroweb.org/guidelines/chronic-pelvic-pain. Here you can download the full guideline and the pocket guidelines.
For an overview see also:
Parsons BA, Baranowski AP, Berghmans B, Borovicka J, Cottrell AM, Dinis-Oliveira P, Elneil S, Hughes J, Messelink BEJ, de C Williams AC, Abreu-Mendes P, Zumstein V, Engeler DS. Management of chronic primary pelvic pain syndromes. BJU Int. 2022 May;129(5):572-581. doi: 10.1111/bju.15609. Epub 2021 Oct 27. PMID: 34617386.

Since 2003, the European Association of Urology (EAU) has published Chronic Pelvic Pain Guidelines which today combine multiple chronic pelvic pain syndromes in a 75-page document with the alternative of a 24-page pocket version and with the only algorithm being for chronic pelvic pain. In this guideline, IC/BPS is now referred to as primary bladder pain syndrome (PBPS).
The authors write that the original EAU classification was inspired by the International Association for the Study of Pain (IASP) classification and much work around what has become known as "pain as a disease" and its associated psychological, behavioural, sexual, social and organ function aspects. After ten years of work developing the initial ideas, an updated version was accepted by the IASP Council for publication in January 2012."
The introduction to the 2022 CPP guidelines states that "In 2016, the guideline was rewritten to be centred around pain instead of being organ-centred".
With this pain focus, there is of course a certain risk of losing sight of equally important urological problems.
While a chronic pelvic pain classification is obviously very appropriate for a pain society such as the IASP, it is somewhat perplexing to comprehend why a urological society duplicated this. All these different pain syndromes are combined per section, including in the tables, which makes it a little difficult to acquire a clear overview of the symptoms, diagnostic evaluation and treatment of any individual syndrome. Perhaps the committee could sometime consider restructuring both the full

guideline document and the pocket guidelines text to make the information on an individual syndrome more accessible, visible and user-friendly?

While the most recent major changes were in fact made in 2021, everyone last year was still so involved with the Covid situation that there was little time to think about the details and consequences of these guideline changes. Today in 2022, with everyone trying to return to some semblance of normality, clinicians, researchers and IC/BPS patients find themselves faced with yet another change in terminology and definitions in line with the International Association for the Study of Pain (IASP) classification and the IASP ICD-11 chronic pain task force's new chronic pain classification which is itself difficult to follow and may present (coding) problems in the future. (See IPBF e-Newsletter February 2022 for a review of ICD-11 https://www.painful-bladder.org/pdf-2/2022-02_Newsletter.pdf)

On the subject of terminology, after years of fragmentation and controversy in the urology world caused by the introduction of BPS in 2003, in recent years the global IC (PBS, BPS, IC/BPS, BPS/IC, IC/PBS, PBS/IC, hypersensitive bladder etc) movement has been making every endeavour to encourage some degree of terminology consensus, with many experts around the world now opting for IC/BPS as can be seen from a glimpse at PubMed. However, this EAU guideline states that no terminology other than PBPS should be used: "Other terms that have been used include "interstitial cystitis", "painful bladder syndrome", and "PBS/IC" or "BPS/IC". These terms are no longer recommended." This seems rather a drastic statement and appears to be at odds with the EAU's involvement in eUrogen for rare diseases where the term interstitial cystitis is used.

How does the EAU define this new primary/secondary terminology:
They write: "Chronic pelvic pain may be sub-divided into conditions with well-defined classical pathology (such as infection or cancer) and those with no obvious pathology but still including biological mechanisms. For the purpose of the EAU's classification, the term "specific disease-associated pelvic pain" has been accepted for the former, and "chronic pelvic pain syndrome" for the latter. In the new ICD-11 these conditions have new names: the former will be called Chronic Secondary Pelvic Pain and the latter Chronic Primary Pelvic Pain. The following classification only deals with Chronic Primary Pelvic Pain Syndromes."

"Chronic primary pain is multifactorial: biological, psychological and social factors contribute to the pain syndrome".
"Chronic Secondary Pain conditions (related to cancer, post surgical, musculoskeletal, visceral, neuropathic, headache/orofacial, other".

With IC/BPS alias PBPS placed in the primary category, is the EAU now saying that IC/BPS is no longer a chronic visceral pain syndrome, since visceral pain is considered secondary? What about IC/BPS in patients with e.g. systemic autoimmune diseases where the IC/BPS could be part of the systemic disease? Would this still be considered primary? Are Hunner lesions truly primary (here referred to as primary bladder pain syndrome type 3C, using the ESSIC 2008 typing system) or should they be secondary, particularly bearing in mind the statement here that they can "lead to a small capacity fibrotic bladder…"?
To add to the confusion, when we look at page 57, 6.1 Evaluation of Treatment, there is a reference to "chronic primary visceral pain"!
There are indeed many practical questions which have not yet been adequately addressed in this regard and a few inconsistencies which need ironing out since the reader is still left unsure what is meant exactly by primary and secondary.

While phenotyping and subtyping are recommended here, there is no clearcut recommendation for the separation of Hunner lesion alias PBPS type 3C despite the fact that ESSIC and many others have published papers in recent years calling for the separation of Hunner lesion.

This EAU document appears to make no mention of the symptom of (painful/sensory) urgency, apparently still "cancelled" for IC/BPS patients in this document. This is sad since an urgent need to empty the bladder has not only been an important symptom for some 200 years, but also a major cause of stress and anxiety in IC/BPS patients and therefore a significant psychosocial aspect.

Rather concerning is the strong or 1a recommendation given to oral pentosan polysulfate sodium (PPS) despite warnings by authorities (including the FDA) and pharma about the risk of retinal pigmentary maculopathy.

On the other hand, while on page 29 it is stated that pain is aggravated by food or drink, the all-important dietary advice is only given a weak recommendation. Difficult to see the logic here bearing in mind the many publications on this aspect and the fact that it plays an important role in all other IC/BPS guidelines and in every patient's life.

- AMERICAN UROLOGICAL SOCIETY (AUA) DIAGNOSIS AND TREATMENT INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME GUIDELINE(2022)

With this link you can download both the pdf full guideline file and the algorithm file.
https://www.auanet.org/guidelines/guidelines/diagnosis-and-treatment-interstitial-cystitis/bladder-pain-syndrome-(2022)
See also:
Clemens JQ, Erickson DR, Varela NP et al: Diagnosis and treatment of interstitial cystitis/bladder pain syndrome. J Urol 2022; https://doi.org/10.1097/JU.0000000000002756.
This paper explains the main amendments made to the 2022 guideline.

The AUA IC/BPS Guideline, which specifically focuses on all aspects of diagnosis and treatment in this disease field, was first published in 2011, amended in 2014 and now amended again in 2022. While basically a national AUA guideline, this detailed document is in practice used internationally at the present time by urologists and urogynaecologists worldwide in both developed and developing countries and therefore its contents have a big impact.

In their amendment paper submitted to Journal of Urology, Clemens *et al* outline the purpose:
"This guideline provides direction to clinicians and patients regarding how to recognize interstitial cystitis/bladder pain syndrome (IC/BPS), conduct a valid diagnostic process, and approach treatment with the goals of maximizing symptom control and patient quality of life while minimizing adverse events and patient burden."
And this is indeed what the purpose of a guideline should be. (Please note the welcome inclusion of the word "patients"!)

A major change in this update – and one that is likely to cause some comment - is that the guideline no longer divides treatments into the hitherto customary tiers, but into categories: behavioural/nonpharmacologic, oral medicines, bladder instillations, procedures, and major surgery. On the one hand, this is understandable since treatment has to be individualised per patient and each patient may have different levels of severity when first diagnosed as well as different comorbidities, subtypes and phenotypes. On the other hand, is this approach going to be absolutely clear to clinicians new to the condition? And what about patients? Doubtless feedback in the coming year will tell.

(Page numbers refer to the full guideline)

Page 6

Primary and Secondary

Comments in the document in relation to the issues of primary and secondary - which have a bearing on ICD-11 - include the following:

- "It is not known whether IC/BPS is a primary bladder disorder or whether the bladder symptoms of IC/BPS are a secondary phenomenon resulting from another cause."
- "Specifically, IC/BPS may be a bladder disorder that is part of a more generalized systemic disorder, at least in a subset of patients."

Page 8

Symptoms: Painful urgency

It is heartening for patients to read that there is now some recognition of the specific IC/BPS type of painful urgency (formerly known as sensory urgency) and that their urgency symptom hijacked in 2002 by OAB has now been at least partially reinstated (if not as yet in the definition):

"There may be qualitative differences in the urgency experienced by IC/BPS patients compared to OAB patients; IC/BPS patients may experience a more constant urge to void as opposed to the classic International Continence Society definition of a "compelling need to urinate which is difficult to postpone." Typically IC/BPS patients void to avoid or to relieve pain; OAB patients, however, void to avoid incontinence. Symptoms of urinary urgency and frequency may precede symptoms of pain. A key characteristic of pain related to IC/BPS is that the pain is worsened with bladder filling ("painful bladder filling") and/or their strong urge to urinate was due to pain, pressure, or discomfort ("painful urgency")."

This could perhaps be further explained by noting that urgency in OAB is typically described as "sudden" and that this is quite different to painful urgency where the sensation of urgency builds up as the bladder fills until it becomes unbearable and the patient is desperate to find a toilet.

Page 12

Guideline Statement 4

It had been hoped internationally that the AUA 2022 update might now opt for earlier diagnosis of Hunner lesion with mandatory cystoscopy which would also exclude other possible conditions including malignancies and tuberculous cystitis. However, although Guideline Statement 4 states that "Cystoscopy should be performed in patients for whom Hunner lesions are suspected", it adds "Since the odds of identifying Hunner lesions are higher in patients over the age of 50, it is reasonable to offer cystoscopy to men and women over the age of 50." (This claim is based on Gross J. et al. 2021). Furthermore, "Cystoscopy should also be considered in those who fail conventional therapies but have never had a cystoscopy before to evaluate for the presence or absence of Hunner lesions". The Panel concludes that "performing cystoscopy for every IC/BPS patient is not advisable since the benefits/risks ratio is unfavorable for younger patients who have a much lower prevalence of Hunner lesions".

This Statement 4 does not take fully into account the risk that the patient who has had no cystoscopy may have been diagnosed with IC/BPS but in fact may have a different condition and even malignancy. The symptoms of non-Hunner IC/BPS and Hunner lesions may be similar or the same and it is therefore difficult to "suspect" HL from symptoms alone. Since HL can be treated quite successfully, it is vital to diagnose it at the earliest possible stage to prevent unnecessary suffering by the patient. This Statement is certainly not a step forward or an improvement for the patient, nor for research.

The differences internationally as to whether a cystoscopy has been performed or not make comparisons of studies from different countries impossible.

The statements regarding age-related prevalence of Hunner lesion certainly deserve a critical look, perhaps internationally in a review paper?

Page 16
Behavioural/Non-pharmacologic Treatments.
Contrary to the weak recommendation in the EAU guideline, the AUA Guideline Statement 9 does indeed discuss diet and avoidance of certain foods known to be common bladder irritants for IC/BPS patients and the importance of the use of an elimination diet.

Pages 20-21
In the AUA Guideline, we see oral pentosan polysulfate sodium (PPS) recommended with Grade B, despite its questionable efficacy, and despite the fact that Guideline Statement 15 gives a black box warning stating:

"Clinicians should counsel patients who are considering pentosan polysulfate sodium on the potential risk for macular damage and vision-related injuries."
It also refers to the new warning label for PPS issued by the FDA in June 2020 stating:

- A detailed ophthalmologic history should be obtained in all patients prior to starting treatment with PPS.
- For patients with preexisting ophthalmologic conditions, a comprehensive baseline retinal examination is recommended prior to starting therapy.
- In addition, a retinal examination is suggested for all patients within six months of initiating treatment and periodically while continuing treatment. If pigmentary changes in the retina develop, then risks and benefits of continuing treatment should be reevaluated, since these changes may be irreversible.

Page 24
Here we read that most Hunner lesions can be diagnosed with office cystoscopy without hydrodistention of the bladder under anaesthesia. If Hunner lesions are not identified, hydrodistention under anaesthesia remains an option.
Until recently, office cystoscopy was considered to be something typical of the USA while Europe and countries elsewhere were always performing cystoscopy under anaesthesia. However, in recent years office cystoscopy has become more common in other countries too. And certainly office cystoscopy is better than no cystoscopy.

Page 33
Guideline Statement 26
The Panel notes that "Treating IC/BPS patients presents a significant challenge in clinical practice. Treatment approaches may be local (directed to the bladder) or systemic, range from behavioral to pharmacological, and may include many types of adjunctive therapy approaches intended to optimize quality of life. Although there are evidence-based data supporting certain treatment approaches for patients in clinical studies, the unsolved question in clinical practice remains: "Who is the ideal patient for a given treatment approach?" Thus, treatment of IC/BPS often requires a trial-and-error approach."
It should be stressed that this trial-and-error approach is precisely what we now need to do our utmost to avoid since it leads to large-scale wastage of drugs and resources and is a cause of immense distress, anxiety and depression in the patient.

Figure one: IC/BPS Diagnosis and Treatment Algorithm
A brief look at the algorithm.

- Here we note the lack of separate algorithm for Hunner lesion which might have been hoped for and which could provide a clearer picture of how to deal with the Hunner lesion patients.

- There is a reference here to complicated and uncomplicated: will less experienced urologists be able to distinguish between these? What do complicated/uncomplicated actually mean: responsive and unresponsive? Or something different?
- Note that there is a box here warning about oral PPS.

The Interstitial Cystitis Association (ICA) has drawn up a useful 3 page summary of the 2022 AUA guideline for patients. An excellent initiative which will hopefully encourage patients to take an active interest in guidelines and understand how important they are for their diagnosis and treatment.
https://www.ichelp.org/wp-content/uploads/2022/05/AUA-IC-Guideline-2022.pdf

- General comment:
A difficult problem in the field of guidelines for IC/BPS is that for some years now there has been a fundamental difference in the approach taken in the United States by the FDA/AUA on the one hand and Europe and Asia for example on the other. The USA prefers to place all patients with pain perceived to be in the bladder in one IC/BPS category, without mandatory early cystoscopy to diagnose Hunner lesion and to exclude other conditions such as malignancies, despite continual references in their guideline to phenotyping and subtyping. However this "all-in-one-pot" approach has failed to lead to any progress in either research or treatment and has certainly not reduced the suffering of the patients. Other parts of the world have hitherto mainly insisted on mandatory cystoscopy which is an essential part of clinical diagnosis but also of any meaningful research programme. But since the EAU does not have a clear, separate guideline for IC/BPS, many other countries, particularly developing countries, have recently felt compelled to follow the AUA guideline but are left in a dilemma regarding whether or not to do mandatory cystoscopy at an early stage.
The ESSIC guideline has always been a valuable option, although currently in need of some updating and revision. Hopefully this will take place soon so that it can once again fill the breach.
An overview of the 2008 ESSIC Guideline can be found at:
https://www.essic.org/_files/ugd/9fec3c_3fc662112bff48d99b4c15f4f6992b69.pdf

REVIEW ESSIC FOCUSSING WEBINARS, COURSES & CONFERENCE

- WEBINAR 3 - Psychology 22 April 2022
Scientific Directors: Claus Riedl & JJ Wyndaele. (recorded video available in the ESSIC member area of the website)
This webinar on psychology was the third in a series organised by ESSIC as a new approach to science, research and especially optimal management of IC/BPS today. Topics have been chosen for this series which don't usually receive the full attention they deserve. Previous webinars in this series focused on Physiotherapy and Behavioural Management & Diet.

In Webinar 3, Dr Claus Riedl, urologist and IC/BPS expert from Austria, discussed the physician and the psychological impact and effects of IC/BPS on daily lives. Professor Dean Tripp, leading Clinical Psychologist in Canada with a special interest in health psychology and pain, spoke on psychological data, approach and management. IPBF chair Jane Meijlink discussed the psychosocial consequences of IC/BPS from a patient perspective.

- WEBINAR - Cistite cronica e cistite interstiziale/bladder pain syndrome. due facce della stessa medaglia? This was held on 20 May 2022 and was a webinar in Italian. Scientific Director: Mauro Cervigni. Speakers were G. Caruso, M. Torella, C. Riedl, R. Damiano and M. Cervigni. (recorded video available in the ESSIC member area on the website)

- ESSIC INTERNATIONAL SCHOOL – 1ST EDUCATIONAL FRENCH COURSE
Paris, 13 May 2022. School Directors: Mauro Cervigni, Jean Jacques Wyndaele

ESSIC International School organised a well-attended 1-day course in Paris on 13 May at the Pullman Bercy Hotel with live speakers as well as international experts on video. Topics were epidemiology & classification, pathophysiology, diagnosis and finally treatment. This was followed by a lively Q&A session and discussions. This was a rewarding experience which could be repeated around the world, according to Professor JJ Wyndaele.

- UPCOMING ESSIC WEBINAR

The ESSIC Focussing Webinar series will continue with the topic of Sexuality on 17 June 2022 at 14.00 hours. This webinar is free of charge. Registration online https://www.essic.org/

- ESSIC 2022 ANNUAL CONGRESS ON IC/BPS

The Essic annual conference is planned for 2-4 December 2022 in Nice, France. Reduced fees will be available for ESSIC members. Further details regarding registration, the preliminary scientific programme and speakers will be available soon on the ESSIC website: https://www.essic.org/.

WEB INFORMATION

INTEGRATE-PAIN

https://integrate-pain-domain-meeting.com/

INTEGRATE-Pain: the "IMI-NIH Transatlantic Emphasis Group on Research And Translation-to-care Efforts for Pain," was established by the NIH HEAL initiative and IMI-PainCare to foster cooperation and consensus in the field of pain research. Dedicated to improving the understanding, management, and treatment of pain, both teams have prioritized common opportunities in preclinical and clinical research, ultimately accelerating the discovery and development of new non-addictive treatments and improving the management of pain. The objectives of INTEGRATE-Pain are knowledge sharing, harmonization of data standards, combination of infrastructures, and coordination of data collection in order to improve the statistical power of data interpretation in future pain research. Given these common objectives, the INTEGRATE-Pain Consortium is currently focused on the development of a common set of Patient Reported Outcomes (PROs), or pain domains (aspects of a disease), as part of Core Outcome Sets (COS) for acute, chronic, the transition from acute to chronic, and episodic/breakthrough pain that are relevant and meaningful to all stakeholders, including patients.

IMI-PainCare

https://www.imi-paincare.eu/

The IMI-PainCare 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) which includes endometriosis and IC/BPS.

Multi-Disciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

https://www.mappnetwork.org/

In 2008 the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH) established the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network. The MAPP Research Network embraces a systemic– or whole–body–

approach in the study of Urologic Chronic Pelvic Pain Syndrome (UCPPS). UCPPS is a term adopted by the network to encompass both IC/BPS and CP/CPPS, which are proposed as related based on their similar symptom profiles. In addition to moving beyond traditional bladder– and prostate-specific research directions, MAPP Network scientists are investigating potential relationships between UCPPS and other chronic conditions that are sometimes seen in IC/PBS and CP/CPPS patients, such as irritable bowel syndrome, fibromyalgia, and chronic fatigue syndrome.

URGE
https://www.urgemedical.org/
Urge is an educational platform for urologists, gynaecologists and all other medical practitioners who would like to learn cutting edge information on how to identify and treat persistent and recurrent UTI and related conditions, in order to enhance care for their patients.

OVERVIEW OF UPCOMING EVENTS

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/

37TH ANNUAL EAU CONGRESS (EAU22)
1-4 July 2022. RAI Amsterdam – Entrance C, Europaplein 24, 1078 GZ Amsterdam
https://eaucongress.uroweb.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/

CONVERGENCES IN PELVIPERINEAL PAIN ANNUAL CONGRESS
Rome, 10-12 November 2022. Lateran University (PUL)
https://www.convergencespp.com/en/agenda/congres/programme2022

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/.

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://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://ww w.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 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.

INFORMATION ABOUT MONKEYPOX

WHO: https://www.who.int/health-topics/monkeypox#tab=tab_1
https://www.who.int/news-room/fact-sheets/detail/monkeypox

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)