

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 63, September 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:

- IPBF Research Update link
- Still worldwide confusion in the field of IC/BPS. Where do the problems lie? A few thoughts and points for discussion
- Review of the ICS 2022 scientific meeting
- 4th ESSIC Focussing webinar and ESSIC session at ICS
- Hybrid Brainstorming Session on Intractable IC/BPS held in Ahmedabad, India, 20-21 September 2022
- GIBS India 7th Annual Congress on IC/BPS 2022
- Review of the Virtual Meeting of IC/BPS Patient Advocates on 24 June 2022
- Overview of upcoming events
- Web information
- Donations & Sponsoring

IPBF RESEARCH UPDATE LINK

To facilitate downloading of the Research Update, please note we have now placed the IPBF eNewsletter and IPBF Research Update in separate pdf files online. Both can be accessed via the IPBF home page: <https://www.painful-bladder.org/> The Research Update September 2022 can also be accessed directly at: https://www.painful-bladder.org/pdf-2/2022-09_ResearchUpdate.pdf We have endeavoured to indicate from which country or countries each abstract comes from so as to provide an overview of where our IC/BPS research is being done. While the USA with its NIH MAPP research project has been the source of much research during the past decade, it is clear that a great deal of important IC/BPS research is currently being carried out in East Asia, including Japan, Taiwan, Korea and in recent years China which now has several research centres.

STILL WORLDWIDE CONFUSION IN THE FIELD OF IC/BPS. WHERE DO THE PROBLEMS LIE? A FEW THOUGHTS AND POINTS FOR DISCUSSION

In the field of IC/BPS, despite many webinars, in the past two years we have really missed the international scientific conferences dedicated to IC/BPS. Consensus on anything seems very far away and this is not helping research into new treatment. There is currently a need for international scientific discussions, in-person, virtual or hybrid, in order to move forward with better coordination of research, guidelines, diagnosis and treatment. Covid has put us back several years and we need to catch up.

Terminology and definitions: While we are seeing an international trend towards the use of IC/BPS as a term, this is by no means universal and every possible variation can still be found in the literature. Definitions and interpretation of which patients should be included under the heading of IC/BPS also vary greatly, thereby distorting prevalence figures, resulting for example in IC/BPS being considered a

common condition in the USA while classified as a rare disease in Europe and other parts of the world. While pain in the bladder may be fairly common, IC/BPS is not necessarily so if correctly diagnosed. When the description of pain as being “perceived” to be in the bladder was first included in definitions, it potentially opened up the field to patients with all kinds of pelvic conditions or damage - where pain coming from outside the bladder is felt by the patient to be in the bladder - to be diagnosed as IC/BPS.

Symptoms: Contrary to what has been implied by chronic pelvic pain classifications in the past two decades, IC/BPS is not exclusively a pain disease. It is a bladder disease comprising pain, pressure or discomfort on the one hand and distressing urinary symptoms such as painful (sensory) urgency and frequency on the other. The pain is exacerbated as the bladder fills. This triad of symptoms – pain, urgency, frequency - is not always made clear to researchers, authorities or health insurance companies, resulting on the one hand in new pain treatments that are ineffective and on the other hand non-reimbursement of effective treatments introduced directly into the bladder (intravesical treatment).

Diagnosis: The confusion concerning prevalence is exacerbated by the fact that cystoscopy to rule out other possible conditions and diagnose Hunner Lesion is mandatory in some countries, but not in others. Without cystoscopy, there are likely to be patients with many other “confusable” diseases wrongly diagnosed and treated as IC/BPS patients. This can be a costly mistake at all levels.

Is (post-operative) damage to tissue, nerves, ligaments etc being missed, leading to a wrong diagnosis of IC/BPS, when a thorough examination of the pelvic floor is not performed?

The above-mentioned emphasis on pain in recent years is possibly the reason why little emphasis has been placed on developing new methods of diagnosing defects in the bladder epithelium/GAG layer. The original potassium sensitivity test was effective but painful. While a modified potassium test was then developed, it is not widely used. A lidocaine test was designed to test whether lidocaine in the bladder calmed the pain. But what is needed is a simple and affordable test that visualises where the bladder epithelium may be defective, allowing toxic urine (e.g. potassium) to penetrate, leaking into the “interstitium” inner layer and causing painful reactions.

Diagnostic guidelines are often unclear or contradictory or far too complex for a busy clinician with only one patient to read through. Clear algorithms and step-by-step instructions are needed. Philosophising and theorising should be reserved for books not clinical guidelines!

Subtyping and phenotyping: effective treatment depends on getting the right treatment to the right patient. At the most basic level, this means knowing whether the patient has IC/BPS with or without lesions. If this subtyping is not done, treatment will continue to be a wasteful, expensive trial & error and understandably patients will continue to “shop” from doctor to doctor. We also have to avoid the pitfalls of mixing patients in studies and drug trials.

Multidisciplinary approach: While everyone talks about the necessity for a multi-disciplinary approach, this either does not exist or is limited to urologist, gynaecologist, counsellor/psychologist, urology nurse, physiotherapist, sometimes a pain doctor and occasionally a sexologist. More gastroenterologists, neurologists, rheumatologists and immunologists need to be involved. Many IC/BPS patients have rheumatoid arthritis, Sjögren’s syndrome, Lupus or fibromyalgia, often with complex systemic symptoms, and coordination of treatment is essential to avoid sometimes severe side effects.

Physician awareness: more awareness needs to be raised at a primary care level to ensure that the patient receives the right diagnosis through correct referral.

Affordability is going to be a key issue in the coming years. No patient and no health system can afford the current trial & error. Better, more accurate diagnosis and treatment tailored to the individual

patient can help to avoid this kind of wastage. While health issues are difficult from an economic point of view now, in the coming few years they could be even more difficult.

REVIEW OF THE INTERNATIONAL CONTINENCE SOCIETY (ICS) ANNUAL MEETING VIENNA 7-10 SEPTEMBER 2022

The International Continence Society (ICS) has led multi-disciplinary continence research and education since 1971 on a worldwide scale through its Annual Meeting and the ICS Journals. With over 3,000 members, ICS is a thriving society of Urologists, Uro-gynaecologists, Physiotherapists, Nurses and Research Scientists with a focus on continence and pelvic floor disorders. Due to the ongoing effects of Covid-19, this 2022 meeting was hybrid.

A most interesting state of the art presentation was given by Professor Christopher Chapple from the UK on the Devastated Bladder and how to identify best evidence. Statistics in medical research were only introduced in the period 1930-1940 with the first randomised controlled trial (RCT) in 1952 and meta-analysis in 1975. In other words, the story of evidence-based medicine (EBM) is very, very short. The EBM concept was only widely introduced 1990-1992, the Cochrane Collaboration in 1993, systematic reviews in 1995 and hierarchy of evidence in 2000. This might lead us to wonder just how evidence-based some of our treatments for IC/BPS really are and perhaps we have to take a new look at what is being called evidence-based in our IC/BPS guidelines... This line of thought became even more alarming when Professor Chapple noted that research findings are quite often false or unreliable! Replication and confirmation are very important, he stressed. Serious side effects may be being missed and systematic use of long term observational studies and patient registries is necessary to find serious and rare side effects. A lot to think about here.

There was a substantial number of abstracts in the field of IC/BPS. There has been a resurgence of interest in mast cells and the role they may play in IC/BPS, particularly in the United Kingdom with abstract 27 presented by Abdelwahab *et al* from the University of Southampton. Also from Southampton was abstract 28 by Yusu *et al* on medical-grade manuka honey, with the suggestion that it might protect the urothelial barrier function in IC/BPS. There was a further abstract (434) from Abdelwahab *et al* from Southampton on both Manuka honey and mast cells entitled: "Medical-grade Manuka honey inhibits mast cell degranulations through downregulation of protein kinase-B/AKT phosphorylation: potential intravesical agent in the management of interstitial cystitis/bladder pain syndrome".

(Editorial note: Interesting to note perhaps is that honey has been used since ancient times for its medicinal and antibacterial properties. See also Mandal MD, Mandal S. [Honey: its medicinal property and antibacterial activity](#). Asian Pac J Trop Biomed. 2011 Apr;1(2):154-60. doi: 10.1016/S2221-1691(11)60016-6. PMID: 23569748; PMCID: PMC3609166.)

Abstract 203 by Kwon *et al* on "Antifibrosis treatment improves detrusor overactivity and chronic bladder pain associated with neural remodeling of central nervous system in a mouse model mimicking interstitial cystitis" was a joint venture from South Korea and Pittsburgh, USA.

Abstract 226 by Liao *et al* from Sichuan, China won the best in category prize for pelvic pain syndromes. This concerned integrating single-cell RNA sequencing with spatial transcriptomics reveals immune landscape for interstitial cystitis. The authors concluded by saying: "We constructed the immune landscape of bladder in women with IC, and then confirmed the characteristics of these immune cell subsets and elaborated the relation and interaction within them. This study sets a precedent for investigating the immune atlas for IC. The immune landscape may provide profound insight into the pathophysiology of IC and work as the foundation for the diagnosis and treatment of this disease in the future."

A further prize went to Arya *et al* from Pennsylvania as best in category prize for e-Health, entitled: Development of a conceptual framework and digital platform for the self management of interstitial cystitis: ERICA (remote engagement with interstitial cystitis AIDE).

They are both to be warmly congratulated on their prizes and it is reassuring to know that we have prize-winning research being conducted in the field of IC/BPS.

Abstract 500 by Marturano *et al* from Italy concerned the "Effects of Covid-19 pandemics on symptoms and quality of life in patients affected by interstitial cystitis/painful bladder syndrome and irritable bowel syndrome, noting that IC/PBS symptoms seem to have worsened during those months of isolation and forced home stay, even though the small number of patients included might have underestimated its impact on their quality of life.

The MAPP network also had an abstract (501) by Sutcliffe *et al* on Association between urologic chronic pelvic pain symptom flares and quality of life, health-care seeking activity, and illness impact and the authors propose that flares are worth considering as additional outcomes in clinical trials and other research studies, as well in clinical practice.

Abstract 503 by Kalfountzos *et al* from Greece concerned IC/BPS and inflammatory bowel diseases. Is there any clinical connection? They concluded that inflammatory bowel diseases and interstitial cystitis/ bladder pain syndrome may have common pathophysiological pathways and parallel clinical manifestations. They suggest that basic research investigation and more clinical trials are needed to definite and highlight this correlation.

Abstract 504 by Topcuoglu *et al* from Turkey looked at sexual dysfunction in women with IC/BPS and whether onabotulinum toxin-A injections improve sexual function.

Van Ginkel *et al* from the Netherlands presented abstract 517 "In vitro: gene expression of GAG synthesizing genes in relation to GAG therapy" concluding that GAG therapy influences urothelial GAG synthesis genes during normal conditions and damage. Adding exogenous GAGs (HA and/or CS) to healthy urothelial cells induces a negative feedback loop for the HA GAG synthesizing genes. This process is also seen in inflammatory conditions whereby GAG therapy attenuates activation of GAG synthesizing genes, thereby suggesting that GAG therapy not only works a liquid barrier patch, but also interacts with urothelial (barrier) repair mechanisms.

We look forward to publication of the full articles.

4TH ESSIC FOCUSING WEBINAR AND ESSIC SESSION AT ICS

The ESSIC Focussing Webinar series dealing with optimal management of IC/BPS continued on 17 June 2022 with its 4th webinar on the topic of Sexuality. Previous webinars dealt with Physiotherapy, Behavioural Management & Diet, and Psychology. The 4th in the series highlighted practical ways of dealing with sexual problems which is a very distressing symptom for IC/BPS patients.

ESSIC also had a short 30-minute session on 17 September at the International Continence Society annual meeting in Vienna with speakers M. Cervigni, JJ Wyndaele and C. Riedl.

HYBRID BRAINSTORMING SESSION ON INTRACTABLE IC/BPS HELD IN AHMEDABAD, INDIA, 20-21 SEPTEMBER 2022

A hybrid brainstorming meeting of urologists and urogynaecologists from different parts of India with an interest in IC/BPS was held on 20 and 21 September 2022 in the city of Ahmedabad which lies to the west of India in the state of Gujarat, at which the topic of "intractable IC/BPS" was discussed. This event was organised by Bhaikaka University, Anand, India. A further unique feature of this meeting was that it was also attended in person by 8 patients with intractable IC/BPS who had been surgically treated by Augmentation Cystoplasty Alone (ACA) without resecting any part of the bladder and who were interviewed about their experiences.

No standard definition for "intractable" exists

Discussions centered around the definition and surgical management of intractable IC/BPS. At present, there is no standard definition of intractable IC/BPS and all the panelists taking part defined intractable IC/BPS in a different way.

The definition that was proposed is as follows:

- Persistence of severe IC/BPS symptoms after adequate treatment with conservative/minimal invasive modalities like oral therapy, intravesical therapy and

therapeutic hydrodistension which includes coagulation of HL, Injection triamcinolone, injection Botox.

- Treatment options for intractable IC/BPS are neuromodulation (sacral or pudendal) or reconstructive surgery

During the meeting, various options were discussed for management of intractable IC/BPS. In India, Interstim neurostimulation is not done routinely and very few urologists have experience of more than 1-2 cases. All surgical options were discussed in detail. The results of surgical options are good but most of the series have a very low number of patients. The following surgical options were discussed.

- Diversion with or without cystectomy
- Supratrigonal cystectomy with augmentation
- Augmentation cystoplasty alone

On average, surgical options have 70-90% results which is better than any other modality of treatment such as oral therapy, intravesical therapy and cystoscopy with hydrodistension. It should be noted that surgical therapy is offered to those patients who have very severe disease and have failed to respond to any other modalities of therapy. Cystectomy with or without diversion has high morbidity even for benign disease such as IC/BPS. The other two surgical options are good with less morbidity.

Dr Nagendra Mishra, urologist in Ahmedabad and a founder Board member of the IPBF, presented his results of ACA performed without removing any part of the bladder. 81% patients are symptom-free with minimum surgical morbidity. From a series of 15 cases, four patients died due to causes unrelated to surgery. Nine of the remaining eleven patients are symptom free while two patients have moderate improvement. Nine patients are voiding by themselves while two require self-catheterization. One patient developed pain after 5 years of being symptom-free but is nevertheless better than previously with less pain. One further patient has no pain but there is persistence of mild frequency. All the patients are much better than they were prior to surgery. ACA is offered to all patients with severe disease irrespective of their bladder capacity or presence or absence of Hunner Lesion.

Eight of these eleven patients were present in the meeting and were called as practice changers. The patients were introduced one by one and were invited to discuss their present condition. ACA does not affect the sexual function of the patient and this was discussed in detail. Sexual function improved as the pain associated with it was relieved in both men and women.

Take home message:

- The negative mindset associated with IC/BPS management has to be changed to positive one.
- Surgical results are good for patients suffering from intractable IC/BPS and surgery is also one of the good options for intractable disease.
- Both HL and non-HL patients can have severe disease.
- Persistence of pain in one patient should not deny 99 other patients the chance of a good quality of life.
- Cystoscopy in IC/BPS patients should be performed by the most experienced urologists. There is a need to train urologists and urology residents to do this.

Editorial note: It is perhaps interesting to note here that other areas of disease have also recently reported that a standard definition of the term "intractable" is lacking and may therefore be subject to widely varying interpretation by clinicians and researchers. There also appears to be some confusion in the literature concerning the difference between intractable and refractory.

GIBS INDIA 7TH ANNUAL CONGRESS ON IC/BPS 2022 - HYBRID CONFERENCE

The GIBS 7th Annual Congress on IC/BPS was held 27-28 August 2022, at Kokilaben Dhirubhai Ambani hospital and medical research institute in Mumbai, India. Due to the ongoing impact of Covid and travel problems, this was a hybrid conference with many people participating or presenting online. Dr Roger Dmochowski from the USA gave an update on the AUA guideline and discussed the many challenges still faced in diagnosis and treatment. There were very many speakers from both the urology and gynaecology world, very often with divergent

approaches to both diagnosis and treatment, once again underlining the lack of consensus worldwide. And while in the past we used to talk about a lack of consensus on criteria, today it seems to be a lack of consensus on almost anything! With cystoscopy not mandatory in all guidelines, treatment becomes trial & error with the risk of other identifiable conditions being missed including malignancies. There is still a lack of awareness among many clinicians, with desperate patients going from doctor to doctor.

There were three excellent patient presentations by patient advocates Balaka Basu from India, Mathilde Scholtes from the Netherlands and Jill Osborne from the USA, with Neelanjana Singh speaking on Diet Therapy.

Full details of the GIBS meeting with a review can be found online in their September 22 newsletter:

<https://gibsociety.com/wp-content/uploads/2022/09/GIBS-NEWSLETTER-SUPPLEMENT-SEPTEMBER-2022-ISSUE-8.pdf>

REVIEW OF THE VIRTUAL MEETING OF IC/BPS PATIENT ADVOCATES ON 24 JUNE 2022

Thanks to the hard work of Mathilde Scholtes (Netherlands) assisted by Balaka Basu (India), IC/BPS patient advocates now have the opportunity to discuss current problems and get updated in online Zoom meetings approximately twice a year. This meeting opportunity is really helpful since many smaller support groups have been struggling during the Covid period. It is also a chance for the experienced patient advocates to help the new generation of advocates to build up their knowledge. Many had been looking at the impact of Covid-19 on IC/BPS patients.

Italy – AICI: Loredana Nasta discussed the Italian AICI project focused on creating a roadmap of IC/BPS treatments, reporting on all products used worldwide for the treatment of IC/BPS, and specifically which products are available in the different countries and which products are marketed under different names in the various countries. They are also looking at what dosages are recommended in different countries. They are planning to send a questionnaire on this to IC/BPS organisations worldwide. This is a very welcome and important project which will fill a gap in our knowledge.

France – AFCl: Barbara Jankowski from the French AFCl informed us that the AFCl attended the first ESSIC International Educational Course held in Paris on 13 May. This was a course with online and in-person speakers and about 40 attendees, mostly young healthcare practitioners, which was in itself welcome news! The four sessions covered epidemiology, pathophysiology, diagnosis and treatment. The AFCl was contacted by Kuste Biopharma, a clinical stage biotechnology company, with information about a new anti-inflammatory drug (Brimapitide) delivered as a bladder instillation currently being tested. Barbara also gave a talk on guidelines, what are they for and why are they important to patient organizations.

Bladder Health UK: Susannah Fraser and Susanne Evans explained that Bladder Health UK had carried out a small survey among their Facebook group about the impact of COVID cystitis. Most people do not seem to be permanently affected was the general conclusion.

India – ICI: Balaka Basu, founder of Interstitial Cystitis India, reported that ICI had organized a virtual meeting of patients at the beginning of the year. It was noted that most had experienced delayed diagnosis of their IC/BPS. ICI conducted online interviews with urologists, urogynaecologists, a dietician and pelvic floor therapists to educate patients. These are available on their [YouTube](#) channel. A great initiative. Covid had a big impact on Indian IC/BPS patients who were taking longer to recover. Many developed new post-Covid symptoms such as reduced lung capacity, food allergies, fatigue, hair loss, joint pain, altered sense of smell and cardiovascular issues. Interestingly, this is quite different to the impression from the UK. Could comorbidities be playing a role?

The Netherlands – ICP: Mathilde Scholtes, Dutch ICP, updated us about the situation in the Netherlands where the GETSBI study into the efficacy of bladder instillations has been started. The ICP has been very busy organizing refresher courses on IC/BPS for medical professionals. These are greatly needed. The ICP has noticed that there are fewer specialized clinics for IC/BPS patients. Part 2 of their patient survey indicates that recurrent urinary tract infections appear to hinder diagnosis of IC/BPS. Furthermore, Covid-19 has led to long waiting lists to get treatment.

Denmark – IC Foreningen: Maria Lukowski reported that the Danish IC support group has published a booklet to educate health professionals. They also have a leaflet for patients who have not yet been diagnosed. Covid had led to major delays in examinations, bladder instillations and other treatment. Some hospitals are trying to reduce waiting lists by holding consultations in the evening.

Canada – The Happy Pelvis: Michelle Milheiras informed us that Canada has a problem with its IC/BPS expert urologists retiring or nearing retirement. And this is indeed a problem faced around the world. How can the younger generation of urology clinicians be encouraged into this field? Canada has noticed that Covid-19 has reinforced the vulnerability of patients due to the uncertainties and delays in care. Challenges have been accessing pain relief, healthcare services and psychosocial support. Gail Benshabat also from Canada added that the delays in getting treatment are huge. People going through a lot of pain don't know what to do and are often desperate.

USA – IC Network: Jill Osborne informed us that studies into maculopathy which may be caused by long-term use of oral PPS is still ongoing, there are about 700 cases now. However, this does not seem to deter some patients who continue to take oral PPS regardless of the risk. There are also many patients who are confused about their diagnosis and question whether it is IC/BPS or something else, for example embedded infection.

USA – ICA: Vicki Ratner MD was the founder of the ICA in the United States, the first IC patient support group to be set up. The ICA managed to get the National Institutes of Health (NIH) interested and involved, with a first conference held in 1987. However, she noted in her presentation that although it's been almost 35 years, little progress has been made to identify the cause(s), despite an immense amount of research. Furthermore, little practical help has been found for the patients and some patients have been driven to taking their own life. She particularly spoke about mast cells which are found in close proximity to blood vessels and nerves. She explained that the hypothesis is that inappropriate mast cell activation may be an integral element and perhaps even the root cause of IC/BPS. She stressed that biopsies taken from patients should be evaluated with special staining and mast cell content should be measured in the urine. A profile of release chemical in the urine could help lead researchers in the right direction since simply relying on the number of mast cells may not be enough. In IC/BPS, mast cells may be hyperresponsive and degranulate more frequently in response to stimuli. Mast cells can also transgranulate via the formation of filopodia (thin finger-like projections) that may attach directly and empty into nerves and blood vessels (endocytosis). She concluded her talk by suggesting that IC/BPS is probably caused by multiple factors, such as chronic inflammation secondary to hyperactivity of nerves, mast cell degranulation and urothelial defects.

International – IPBF: Jane Meijlink, Chair IPBF, discussed the controversy surrounding the term "urgency", explaining that for almost two decades the "sensory" (painful) type of urgency due to intolerable pain or unpleasant sensation as typically experienced by IC/BPS patients has no longer been officially recognized, researched or treated as a symptom of IC/BPS, thereby misrepresenting the disease IC/BPS. Until 2002, urgency was associated with two types of dysfunction: (a) Overactive detrusor function (motor urgency); (b) Hypersensitivity (sensory urgency).

This changed in 2002 in the *The standardisation of terminology of lower urinary tract function: Report from the Standardisation Sub-Committee of the International Continence Society*. Abrams P, Cardozo L, Fall M, et al. *Neurourol Urodyn* 2002;21:167–78. (Also published in: *Urology*. 2003 Jan;61(1):37-49) Urgency now became the complaint of a sudden compelling desire to pass urine, which is difficult to defer, also stating that urgency, with or without urge incontinence, usually with frequency and nocturia, can be described as the overactive bladder syndrome, urge syndrome or urgency-frequency syndrome.

In *A standard for terminology in chronic pelvic pain syndromes: A report from the chronic pelvic pain working group of the international continence society*. Deggweiler R, Whitmore KE, Meijlink JM, Drake MJ, Frawley H, Nordling J, Hanno P, Fraser MO, Homma Y, Garrido G, Gomes MJ, Elneil S, van de Merwe JP, Lin AT, Tomoe H. 2017 Apr;36(4):984-1008. doi: 10.1002/nau.23072. Epub 2016 Aug 26, the ICS now produced the following definition:

“Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS). Persistent or recurrent chronic pelvic pain, pressure or discomfort perceived to be related to the urinary bladder accompanied by at least one other urinary symptom such as an urgent need to void or urinary frequency.”

An article published in 2020 (*An urgent case for sensory urgency: A patient perspective*. Meijlink J. *Neurourol Urodyn*. 2020 Sep;39(7):2008-2010. doi: 10.1002/nau.24457. Epub 2020 Jul 10. PMID: 32648972) proposed reintroducing either sensory urgency or painful urgency. Since then, the term painful urgency has been seen in the literature and also in the AUA 2022 IC/BPS Guideline update.

So while some progress has been made, sensory/painful urgency is still not included in lower urinary tract standardisation documents, nor is urgency included in definitions of IC/BPS and is therefore still considered by some people not to be a symptom of IC/BPS. Furthermore there are now some younger urologists who have been led to believe that all urgency is “sudden” (-> urge incontinence) which creates completely the wrong picture of the IC/BPS patient

OVERVIEW OF UPCOMING EVENTS

RESEARCH ADVANCES FOR UROLOGIC CHRONIC PELVIC PAIN SYNDROME: INFORMING THE NEXT GENERATION OF CLINICAL STUDIES

17-18 October 2022. Virtual meeting.

<https://www.niddk.nih.gov/news/meetings-workshops/2022/Research-Advances-Urologic-Chronic-Pelvic-Pain-Syndrome>

CONVERGENCES IN PELVIPERINEAL PAIN ANNUAL CONGRESS

Rome, 10-12 November 2022. Lateran University (PUL)

<https://www.convergencespp.com/en/agenda/congres/programme2022>

SOCIETY OF URODYNAMICS, FEMALE PELVIC MEDICINE & UROGENITAL RECONSTRUCTION (SUFU) SUFU 2023 WINTER MEETING

March 7 - 11, 2023, Grand Hyatt Nashville, Nashville, TN, USA

<https://sufuorg.com/home.aspx>

EUROPEAN ASSOCIATION OF UROLOGY – EAU 23

10-13 March, Milan Italy.

<https://eaucongress.uroweb.org/eau23-the-38th-annual-eau-congress/>

AMERICAN UROLOGICAL ASSOCIATION - AUA 2023

28 April-1May 2023, Chicago,

<https://www.auanet.org/AUA2023>

WEB INFORMATION

INTEGRATE-PAIN

<https://www.imi-paincare.eu/NEWS/files/IMI-Paincare-2020-003.php>

<https://heal.nih.gov/node/36276>

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.

PREFER

<https://www.imi-prefer.eu/>

PREFER looks at how and when it is best to perform and include patient preferences in decision making during the medical product life cycle. Patient stakeholders are included at every level of the project. The end-result will be recommendations to support development of guidelines for industry, Regulatory Authorities and HTA bodies.

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

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/CPSP, 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/CPSP patients, such as irritable bowel syndrome, fibromyalgia, and chronic fatigue syndrome.

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://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 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.

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