

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 64, January 2023

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
- Canadian Sleep Deprivation Impact Survey Now Online: IC/BPS Patients Invited to Participate!!
- Review of NIH/NIDDK Virtual Meeting October 17–18, 2022
- Review of Dutch Symposium on Inflammatory Bladder Disorders Held in Amsterdam 7 October 2022
- Review of Global IC/BPS Patient Advocates Virtual Meeting, 10 December 2022
- IMI-PainCare Webinar for Patients, 6 March 2023
- Books: Sensation in the Pelvic Region by Jean Jacques Wyndaele
- Web Information
- Overview of upcoming events
- 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 January 2023 can also be accessed directly at:

https://www.painful-bladder.org/pdf-2/2023-01_ResearchUpdate.pdf

We have endeavoured to indicate in the Research Update from which country or countries each abstract comes from so as to provide an overview of where our IC/BPS research is being done. The IPBF Research Update provides a wider view of the field by including some interesting papers on diseases and disorders that often occur with or are related to IC/BPS. We have also included some interesting research on the impact of Covid-19 with a bearing on our field.

- Open Access

Today we are seeing far more open access papers than in the past and this is particularly useful for patient advocates and their organisations who wish to learn more about scientific developments so as 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.

Useful open access articles this time include an overview from Chengdu, China: “Broaden horizons: the advancement of interstitial/cystitis/bladder pain syndrome” by Jin Li and colleagues, and a review from Taiwan on “Current understanding of the pathophysiology and novel treatments of interstitial cystitis/bladder pain syndrome” by Jia-Fong Jhang and colleagues which reviews recent advances. Many people may be interested in the paper by J Curtis Nickel from Canada on “Managing Interstitial

Cystitis/Bladder Pain Syndrome in Female Patients: Clinical Recipes For Success” where he gives recipes for instillations which he has found useful in his career.

Recently, we have seen new interest in urinary tract infections (UTIs) and methods of diagnosis. IC/BPS patients, with a compromised urothelium, are particularly vulnerable to UTIs, including with low levels of bacteria which may be missed in current (outdated) diagnostic methods which have many shortcomings, as noted by Chieng and colleagues in their open access paper “The clinical implications of bacterial pathogenesis and mucosal immunity in chronic urinary tract infection”. There are flaws in the dipsticks used to diagnose UTIs in primary care and often used by IC/BPS patients at home to check for infection, with experts suggesting that up to 50% of UTIs may be being missed.

In a further paper, although not open access, Wolfe and colleagues looked at “Detection of bacteria in bladder mucosa of adult females”, which could be of potential interest to us.

CANADIAN SLEEP DEPRIVATION IMPACT SURVEY NOW ONLINE: IC/BPS PATIENTS INVITED TO PARTICIPATE!!

Dr Dean A. Tripp (Professor of Psychology, Anesthesiology and Urology, Queen’s University in Kingston, Ontario, Canada) and his research team member Alexander Kelly are working on a thesis project in the Pain Lab and wish to invite patients who have received a diagnosis of Interstitial Cystitis/Bladder Pain Syndrome (IC/BPS), who are 18 years of age or older, and who can read/write English to participate in their brief online research survey so as to “hear” what patients really experience. Whether symptom-free or going through a challenging time, they would like to hear from you. This survey is interested in sleep and pain cycles. The survey which takes approximately 25 minutes to complete asks biological, psychological, and social questions, in the hope that the information will ultimately help the global IC/BPS community.

After the first baseline survey, patients can opt to participate in two follow-up surveys (4 and 8 weeks after baseline). However, this is entirely optional. Participants can complete the first baseline survey and not leave their contact information if they do not want to be contacted regarding the other two surveys.

The survey link is:

https://queensu.qualtrics.com/jfe/form/SV_0GqrG6JjmCuNMR8

Contact person: Alexandra Kelly, Queen’s University, Humphrey Hall, Kingston ON Canada K7L 3N6

Email: 18aak17@queensu.ca or dean.tripp@queensu.ca

A REVIEW OF THE NATIONAL INSTITUTES OF HEALTH (NIH)/NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES (NIDDK) VIRTUAL MEETING OCTOBER 17–18, 2022

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

This keynote virtual meeting organized by the NIH/NIDDK in the USA and attended by over 140 participants from the United States and many other countries provided a “global” forum for the exchange of new insights into the Urologic Chronic Pelvic Pain Syndrome (UCPPS) - which encompasses both IC/BPS and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) - on which the NIDDK’s Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network was based. A central goal of the meeting was to promote the translation of new findings into future, evidence-based clinical trials for UCPPS that will hopefully ultimately improve patient care.

The meeting highlighted findings from the MAPP Network and others working in the field as well as advances in other related areas. Scientific themes included phenotypic subgrouping strategies for targeted interventions, mechanistic insights in support of new targets and phenotypes, improved

evidence-based definitions and outcome measures and designs for clinical trials informed by new research insights. There were also breakout sessions that facilitated active participation by all attendees. This “virtual” format allowed many health professionals and patients/patient advocates, who would not otherwise have been able to travel in these difficult times, not simply to attend but also actively participate.

Younger generations do not perhaps realize what an important role the famous NIDDK symposiums on interstitial cystitis used to play in the early years in educating, stimulating research and networking worldwide. They were wonderful, globally attended occasions, highlights in the field of IC/BPS. But the world has changed and seems to be changing even more by the minute. While nothing can fully replace personal networking, the format of this virtual meeting with its breakout sessions set the tone for more in the future.

It is now vital that we have more international contact and coordination and that all the different research centres in the world have the opportunity to come together, exchange ideas and pool resources, whether in a virtual, personal or hybrid format.

Following the Plenary Presentation outlining developments so far, the interactive Patient Forum was particularly interesting with interviews with several patients who shared their personal experiences living with IC/BPS. Each had severe pain problems but when asked what most wrecked their quality of life, they referred to their urinary symptoms, with the frequent and urgent need to find bathrooms dominating every minute of their life. It should be noted here that in the past two decades, so much emphasis has been placed on pain and pain syndromes that the urinary symptom aspect has often been sidelined and neglected. It has sometimes been forgotten that this is basically a hypersensitive urinary bladder disease. This Patient Forum was a clear sign that researchers must talk to the real patients to find out what the real disease is with its real symptoms: both urologic and pain. Research without the patient perspective does not work.

Another area of special interest in the meeting was that of phenotypic subgrouping strategies for targeted, tailored treatment of the patient. All we really have in concrete terms at present is the distinction between Hunner Lesion and non-lesion IC/BPS. In recent years, phenotyping has been a buzzword and many concepts have been put forward, but there is still no clear concrete picture that would really improve the current trial & error situation for the patient, a situation which is increasingly becoming unaffordable at all levels. A problem with phenotypic treatment is that many patients have several phenotypes, not just a single phenotype. How to deal with this remains an unanswered question.

While the MAPP project has looked at IC/BPS in a wider context - combining IC/BPS with CP/CPPS and involving a wide range of comorbidities in studies - we have not seen very much in the field of IC/BPS combined with systemic autoimmune diseases such as Sjögren’s syndrome and Lupus (SLE). Is the systemic autoimmune disease the cause of the bladder hypersensitivity in these patients? Hopefully someone somewhere will take this up, perhaps in coordination with organisations and foundations focused on these diseases.

Another area that still needs attention - or at least some discussion - is the fact that IC/BPS is considered a common disorder in the United States, whereas in Europe – and other countries around the world – it is classified as a rare disease. This indicates that there may be an important difference in diagnostic techniques, including the need for mandatory cystoscopy to exclude confusable disorders.

The NIH/NIDDK is currently finalising a detailed summary of the meeting which will be posted online. In the meantime, the following websites may be useful:

- **MAPP Network website** <https://www.mappnetwork.org/>

Please note that this website is currently undergoing a major re-working and update this year aimed at better highlighting publications (>100 to date; most are listed here in “MAPP Publications”). It will also contain links to the new **MAPP DataView tool** – this is being developed as a visualization tool for all MAPP data for interested investigators to better understand the data and biological measures collected.

- **NIDDK Central Repository** <https://repository.niddk.nih.gov/home/>

All MAPP Network Phase I and Phase II study clinical data, biological samples, neuroscans, key documents etc. are being assembled here for public access by the larger research community. This is expected to be completed by Spring, 2023 and will be the location for interested researchers to access these resources for further study.

REVIEW OF DUTCH SYMPOSIUM ON INFLAMMATORY BLADDER DISORDERS HELD IN AMSTERDAM 7th OCTOBER 2022

While this symposium in inflammatory bladder disorders, held in Amsterdam, was an entirely Dutch event, it was such a unique urological programme that we would like to share it with everyone internationally and encourage similar projects elsewhere.

In recent years, we have tended to see IC/BPS exclusively presented within a framework of chronic (pelvic) pain, with urinary symptoms all too often sidelined or even ignored, including by authorities. This symposium, chaired by urologists Lara Gerbrandy-Schreuders, Afina Glas and Dick Janssen, looked at the whole field of “cystitis” – bladder inflammation – including interstitial cystitis, ketamine cystitis, eosinophilic cystitis, radiation cystitis, haemorrhagic cystitis induced by the BK virus or chemo-therapy and the condition known as cystitis glandularis. Dr Wouter van der Sanden discussed the damage – sometimes horrendous – to the lower urinary tract that can be caused by ketamine when used as a party drug, and which can ultimately lead to surgery and a stoma once the young people become addicted. This type of addiction has now spread worldwide.

The second part of the programme looked at individual cases, including end stage interstitial cystitis and candida cystitis. This included a discussion of the burden on healthcare of recurrent urinary tract infections in patients with IC/BPS. It was recommended that this should be given more attention.

The third session provided an update in treatment varying from oral treatment to GAG replenishment, cystectomy, pain blocks and hyperbaric oxygen therapy with an excellent overview of IC/BPS medical treatment given by Dr Erik Arendsen. Dr Dick Janssen followed with an overview of GAG replenishment therapy and specific treatments for Hunner lesion. He also gave an update of the ongoing GETSBI study into GAG therapy for Hunner lesion. It was a most interesting day, looking at IC/BPS in an inflammatory context and a glimpse of rare inflammatory bladder conditions.

REVIEW OF GLOBAL IC/BPS PATIENT ADVOCATES VIRTUAL MEETING, HELD ON 10 DECEMBER 2022

This virtual meeting and global update was attended by patient advocates from many different countries, even though it was the middle of the night for some. It was clear that the impact of Covid-19 is by no means over. Those patients who have had Covid one or more times are often still suffering from the effects on their symptoms including on the symptoms of any comorbid conditions.

Zita Gódorné Hazenauer from IC Hungary reported that due to Covid the situation was very difficult with too many people (both patients and medical professionals) unreachable or unavailable. In Hungary, bladder instillations are the most commonly used therapy for IC/BPS and widely accepted.

As in the case of so many countries, patients find most of their information via social media which play a very influential role and all too often promise patients a “magic” solution to solve the symptoms of IC/BPS.

Certainly when you look at social media patient groups, you can see that patients are buying every imaginable pill and potion online in the hope that these will fulfil the promises made on the relevant website. This does seem to be an indication that professional treatment is failing many patients.

Susannah Frazer explained that Bladder Health UK was in the process of launching a small survey in conjunction with a corporate partner aimed at understanding the impact of Covid on the patients and on treatment for those with IC. Healthcare systems everywhere have been affected, leading to shortages of personnel and long waiting lists for patients to see a doctor. Access to primary care/GPs is still restricted. Useful to know that the updated NHS page on IC is available at <https://www.nhs.uk/conditions/interstitial-cystitis/>. It was good to hear from Susannah that NHS Diagnostics and the National Institute for Clinical Excellence are now looking at NHS testing of urine as they recognize that current testing is unreliable: “Standard urine tests used in GP surgeries and hospitals may not pick up all infections of the bladder.” Susannah also reported that there is still a lack of adequate research (multi-centre randomized control trials) to confirm or exclude chronic UTI as a potential cause of IC/BPS in some patients.

From Barbara Jankowski from AFCI France we heard that they are looking at all possible ways of raising awareness of IC. Barbara raised the important issue of the impossibility of patient advocates being able to afford registration fees for many international conferences. It is very important to ensure that patient advocates are able to attend these conferences so as to stay abreast of developments. Some patient advocates have experience in being able to register as Press.

Michelle Milheiras from The Happy Pelvis in Canada (<https://thehappypelvis.ca/>) reported that they have launched a fact sheet on IC/BPS (<https://thehappypelvis.ca/what-is-interstitial-cystitis/>) and a podcast. The pandemic has made what was already a difficult situation for IC/BPS patients even worse with increases in delays/waiting lists as practice caseloads become unmanageable. There is a shortage of doctors, with Ontario family doctors changing careers or leaving practice due to Covid burn-out. The support group is concerned about these developments.

Mathilde Scholtes from ICP in The Netherlands reported that the Dutch healthcare system had also been experiencing extreme pressure and long waiting lists due to Covid. The Netherlands is also currently experiencing a concerning problem with medicine shortages. The course for GPs started in March will be continuing as a webinar until March 2024. So far, no fewer than 659 GPs have participated. There is increased awareness of urinary tract infections in the Netherlands and the ICP patient survey included some questions on UTIs. An IC/BPS bladder is even more susceptible to infection than a healthy bladder and can greatly exacerbate the existing IC/BPS symptoms. The ICP patient survey part 2 was distributed to members in December. It concerns symptoms, diagnosis, UTIs and quality of life in addition to medical and alternative/complementary treatment for IC/BPS patients.

The New Zealand IC/BPS support group is now 30 years old and was one of the first support groups to be formed. Chair Dot Milne, herself an IC/BPS patient and a urology nurse, told us that the group also provides IC/BPS education for nurses and GPs. The support group newsletter is also sent to urologists. Dot emphasized that nurses can play a most valuable role in the treatment of IC/BPS patients. They take an holistic approach, they are more available and accessible, can educate and communicate with the patients and provide follow up. Patients needed a lot more support during the Covid period. She

also stressed that patients need reliable information about the (potentially dangerous) interaction of medicines.

Jill Osborne from the IC-Network USA reported that a new AUA IC/BPS guideline was published in 2022. She also pointed out that many clinical trials have unfortunately proven to be a waste of resources due to a mix of phenotypes within a single study. It is now being realized that you must first phenotype before including patients in a trial. Platelet-rich injections seem to be being received well in the USA. Jill noted that a new generation of urine testing is being used in the USA, produced by MicroGenDX and this test can identify bacteria, viruses and fungal infection.

Many thanks are due to Mathilde Scholtes for organizing this online meeting. We are all very grateful. Patient support groups greatly benefit from this global contact which helps to keep everyone updated with developments and also gives patient advocates around the world the feeling that they are not working alone in a vacuum.

IMI-PAINCARE WEBINAR FOR PATIENTS 6 MARCH 2023

The International Painful Bladder Foundation (IPBF) has been part of an exciting research collaboration known as IMI-PainCare for several years now and this project will be drawing to a close this year. The project is likely to shape pain research for years to come including on several crucial issues relevant to patients. Find out more here: <https://www.imi-paincare.eu/>

The IMI-PainCare team IS organizing a webinar for patients to learn more about the project and its relevance for them. It will take place on 6 March 15:00-17:00 CET. You can find more information about the programme and register here: https://us06web.zoom.us/webinar/register/WN_Lv-ByMWvRjemapHyxFgAqA



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BOOKS

SENSATION IN THE PELVIC REGION

Author: Jean Jacques Wyndaele

This book concerns sensation highlighted from afferent innervation, provides a comprehensive overview and a guide of diagnosis and treatment.

DOI <https://doi.org/10.1007/978-3-031-16964-9>

Publisher: Springer Cham

Hardcover ISBN978-3-031-16963-2 Published: 19 November 2022

eBook ISBN978-3-031-16964-9. Published: 18 November 2022

Number of Pages: 176

This new book by Professor J. J. Wyndaele from Belgium covers sensation in all major components of the pelvic region. The small pelvis contains many different structures and viscera, and sensations elicited there are important for regulating a normal daily life and for warning that something may be going wrong. It is hoped that this compilation of most data available on sensation will be of interest to the reader and will encourage more research. This book is intended for all with an interest in pelvic functions and interactions between the different structures, specialists in urology, gastroenterology, sexuality, pain, pelvic floor function and dysfunction, paediatricians and geriatricians, neurologists, students and those in training.

For more detailed information, go to <https://link.springer.com/book/10.1007/978-3-031-16964-9>

WEB INFORMATION

EUROPEAN REFERENCE NETWORK – eUrogen for urogenital diseases

Contrary to the situation in the USA, IC/BPS is classified as a rare disease in Europe. In eUrogen, the term used is “interstitial cystitis”. Read more: <https://eurogen-ern.eu/>

NATIONAL VULVODYNIA ASSOCIATION (USA)

Here you can find a link to our most recent [Research Update Newsletter](#). You can also view the current and previous Research Update Newsletters on the NVA website by clicking on the following link: <http://www.nva.org/research/research-update-newsletter/>.

OVERVIEW OF UPCOMING EVENTS

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. This congress includes a patient day with a session on different types of cystitis including IC/BPS.

<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>

ESSIC 2023 – SAVE THE DATE!

6-8 Jul 2023, New York, USA.

Meeting Chair: Robert Moldwin, ESSIC President: Mauro Cervigni

The meeting will include keynote lectures, debates, panel discussions and more, as well as networking events. Check the ESSIC Congress website to keep updated and to subscribe to the ESSIC 2023 newsletter. Information & updates: www.essic.org – www.essicmeeting.eu

GIBS 2023: 8TH ANNUAL CONGRESS ON INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME

26-27 August 2023, Mumbai, India. Theme: “Compassion & Care for Bladder Flare”.

www.gibsociety.com

13th CONGRESS OF THE EUROPEAN PAIN FEDERATION EFIC

20-22 September 2023, Budapest, Hungary

<https://europeanpainfederation.eu/>

53rd ANNUAL MEETING OF THE INTERNATIONAL CONTINENCE SOCIETY (ICS 2023)

Wed, 27 Sep - Fri, 29 Sep 2023

<https://www.ics.org/2023>

CONVERGENCES PP ANNUAL MEETING 2023

19-21 October 2023 in Barcelona, Spain.

<https://www.convergencespp.com/en/>

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)

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