

## REVIEW OF THE ESSIC ANNUAL SCIENTIFIC MEETING

### Amsterdam, The Netherlands, 5-7 December 2019



The **ESSIC 2019 annual scientific meeting**, held at the DoubleTree by Hilton Hotel in Amsterdam and enthusiastically chaired by **Dick Janssen MD (NL)**, was attended by some 170 participants from no fewer than 33 countries around the world including doctors, nurses, physiotherapists and patient advocates and all these groups were well represented among the speakers.

The meeting 5-7 December coincided with the Feast of St Nicholas which is celebrated in the Netherlands on 5 December. The opening day was consequently a festive occasion with a personal visit by St Nicholas (“Sinterklaas” in Dutch) who took time off from his busy 5 December gift-delivery schedule to wish the delegates and speakers every success!

A successful innovation this year was the organization of 3 interactive workshops on the Saturday morning: for physiotherapists, nurses and the new ESSIC committees.

This 2019 meeting was remarkable for its great atmosphere, high level of interaction and particularly the tremendous enthusiasm from everyone. It was encouraging to see younger generations of health professionals, including nurses and physiotherapists, participating to the full. The meeting was also attended by far more patient advocates than ever before, many of whom had travelled long distances, including from South Africa, Israel, Canada, USA and India as well as many different European countries. Some are new to the field and ESSIC 19 therefore provided a perfect learning and networking opportunity.

In addition, the Dutch IC patient association (ICP) had taken the opportunity to host and organize an international patient advocacy lunch and meeting directly after the ESSIC meeting finished on Saturday 7 December. This was a huge success and was also attended by a number of medical professionals who support patient organizations in medical advisory boards. Hopefully this will ultimately lead to some kind of global alliance. Many thanks are due to the ICP and especially Mathilde Scholtes for their hard work in organizing this and to Dick Janssen for kindly chairing the meeting.

The theme of the ESSIC 19 meeting was “the right multidisciplinary treatment for the individual patient”. The meeting also emphasized the need for appropriate phenotyping/subtyping with many speakers recommending that Hunner lesion should be split off from non-lesion disease or, at the very least, that lesion patients should not be combined with non-lesion patients in drug trials or studies. An important message was that progress means sorting out the patients into relevant groups so that each group gets appropriate treatment, while at the same time ensuring that in a clinical setting each patient receives individual, personalized, usually empiric treatment.

This review is alas only able to pick out a few highlights, an unenviable task bearing in mind that there were many excellent speakers at this meeting.

The meeting opened with an interactive discussion of cases by **Philip Hanno MD (USA)** to warm up the delegates and give them a taste of the complexities of IC/BPS in individual patients, the different forms it can take and patients who may have been given the wrong diagnosis.

Speaking on non-lesion IC/BPS, ESSIC President **Jean-Jacques Wyndaele MD, (Belgium)** emphasized the absolute importance of cystoscopy to differentiate between lesion and non-lesion. In his overview of treatment possibilities, he noted that while GAG replenishment to reduce leakage due to epithelial layer damage is an important aspect of treatment for many patients, it is often not reimbursed. Heparin is then a cheap alternative. However, there are patients who do not respond to GAG therapy and research is needed into these non-responders to see what is different with their bladder. Do these patients have a different bladder pain syndrome with a different cause? **A key goal must be how to select patients for the right treatment.** He noted that there are multiple national and international guidelines in use, with differences in nomenclature, definitions and recommended diagnostic investigations. The overall evidence for the majority of treatments for IC/BPS is of low quality. This is why he recommends an empirical approach. He emphasized that larger randomized trials are needed. A strong ESSIC guideline is needed and would be very beneficial.

Q&A: While JJ Wyndaele had recommended approaching treatment on the basis of starting with less invasive therapy, **Sandor Lovasz MD** from Hungary pointed out that if it has taken a patient years to get a diagnosis, it may be necessary to start with more invasive treatment, going straight to intravesical treatment.

A particularly interesting talk in this first session was by **Erich Taubert MD (NL)** on subtyping Hunner lesions (ESSIC type III): different lesion phenotypes and Pancystitis, with beautifully clear photos and videos. Hunner lesions appear to be more common than previously believed and may even be a different entity altogether. In his own practice, 62% of confirmed IC/BPS patients were found to have Hunner lesions. He noted that before HL there may be bladder vulnerability. HL may be “hidden” before becoming identifiable. Hunner lesions may have different appearances. HL may be preceded by a pancystitis phase. In flare-ups, pancystitis can often be seen. HLs tend to connect and connected HLs form contractures. This was a wonderful, realistic presentation, looking at all types of lesions and following the development of lesions over several years.

A high-quality atlas is now urgently needed for teaching purposes and Erich Taubert certainly set a high standard in this respect with his presentation. An atlas would be a major step towards better diagnosis since while many doctors may have great difficulty in diagnosing a Hunner lesion, there is also a risk that they may sometimes be misdiagnosing carcinoma in situ as Hunner lesion.

Pros and cons of different treatments for HL were discussed by **Afina Glas MD (NL)** and **JJ Wyndaele**, looking at Holmium YAG, TUR and Electrocautery. We don’t know what is better, Afina Glas concluded. However, electrocautery coagulation or laser is safer than transurethral resection, in her view.

**Dick Janssen MD (NL)** presented the talk on pharmacological treatment by **Claus Riedl MD (Austria)** who was unable to attend, looking at oral drugs with their systemic effects and side effects, intravesical drugs and analgesics on the basis of the different guidelines. Each guideline gives drugs a very different recommendation, despite being based on the same studies. This is extremely confusing! Although the AUA guideline states that long-term antibiotics should not be used, it was suggested that there may be patients who really need these. While the treatments of “significant value” for BPS in the EAU guideline include immunosuppressants such as azathioprine, cyclosporine A and methotrexate, these can have devastating side effects in patients with IC/BPS. This prompted Dick Janssen to take a look at systemic therapies used in the rheumatic autoimmune diseases and which urologists treating IC/BPS patients need to be aware of, with a list of reported side effects including in the bladder. This emphasizes the need for close consultation with the rheumatologists treating these

patients. While one guideline states that corticosteroids should not be used, another says they are of limited value, but a third recommends their use!

Stratification is now essential in drug trials with a focus on different phenotypes. Most of the old studies need redoing since in the past all patients were mixed up in any given trial: lesion, non-lesion etc.

**Mauro Cervigni** MD (Italy) then introduced some crucial issues: Where are we now, where are we going and where should we go? Future directions should be to identify bladder-specific pathology, identify one or more biomarkers, identify bladder-specific immunological processes, continue to work on phenotyping, develop epidemiologic screening tools and establish international patient databases.

**Quentin Clemens** MD (USA), chair of the **MAPP Research Network**, gave us a report on the progress of their research. M APP is the Multidisciplinary Approach to the Study of Chronic Pelvic Pain. It is a multi-institutional, collaborative network funded by the NIH/NIDDK and dedicated to the study of IC/BPS and CP/CPSP which they together describe as Urologic Chronic Pelvic Pain Syndrome (UCPPS). Its scientific objectives are:

- to address underlying disease pathophysiology and natural history utilizing patient cohorts, biospecimens and animal models;
- to provide new information to inform patient management and future clinical trial design (important patient phenotypes/subgroups, drug targets, etc).

The rationale behind the MAPP project is that progress has been too slow due to overemphasis on the bladder and prostate as the source of disorders without considering more systemic contributions; poor understanding of patient sub-types/phenotypes - it is unlikely that all patients will respond to a given therapy; insufficient efforts to coordinate clinical and basic research expertise, involve disciplines beyond urology, incorporate patient-centred data. MAPP phase I covered the period 1 July 2008 to June 2014, MAPP phase II July 2014 to June 2022.

**Francisco Cruz** MD (Portugal) gave an Update on the IMI-PainCare (TRiPP) Research Consortium ([www.imi.europa.eu](http://www.imi.europa.eu)). IMI – Innovative Medicines Initiative – is a public/private partnership aiming to improve the competitive situation of the European Union in the field of pharmaceutical research. IMI-PainCare comprises Patients, Academia and Industry. The main hypothesis to be tested is that: endometriosis-associated pain (EAP) and bladder pain syndrome (BPS) are primarily chronic pain conditions featuring similarities in mechanisms underlying pain generation and maintenance, albeit associated with specific pathological lesions and end-organ symptoms. It comprises 3 sub-projects: PROMPT, Bio-Pain and TRiPP.

The main hypotheses that will be tested by IMI-PainCare are as follows:

**PROMPT:** hypothesis is that PROMS (Patient Reported Outcome Measures) provide valuable information which help healthcare professionals to follow up on treatment success and identify patients at risk of chronification.

**BioPain:** hypothesis is that effect sizes of analgesic actions can be translated between rodents, healthy volunteers undergoing surrogate models of pain sensitization and patients suffering from chronic pain.

**TRiPP:** hypothesis is that the pain experienced by women with EAP and BPS is generated and maintained by mechanisms eventually similar to those found in other chronic pain conditions.

The focus is on two indications with common pain symptoms: endometriosis and IC/BPS. The key concepts of TRiPP are that:

1. Women with chronic pelvic pain due to EAP or BPS can be stratified into mechanistically and/or prognostically relevant clusters.
2. Women show biomarker profiles associated with vulnerability to develop pain and/or to maintain pain, independent of the underlying peripheral disease.
3. Pre-clinical models that fully reflect human phenotypes will have enhanced translational value.

A main objective is to improve disease understanding and optimize animal models to identify new treatment options for patients.

**Mariangela Mancini** MD (Italy) and ePAG representative **Serena Bartezzati** (Italy) together reported on the progress of ERN (European Reference Network) eUrogen Workstream 2.5 BPS. Patients play an important role as ePAG representatives. The patient contribution to research is to balance what evidence-based medicine recommends with what is possible, desirable and acceptable for the individual patient. Patient Driven Research (PDR) is innovative and growing rapidly. Developing Biobanks and Registries to give us fair (findable, accessible, interoperable, reusable) data to use in controlled research within the ERNs could give us important results.

**Rajesh Taneja** MD (India) gave an overview of experiences from India which has a population of a breathtaking 1,300,000,000, with 3,000 urologists and 40,000 gynaecologists. India has produced an Indian diet book for Interstitial Cystitis (authors Neelanjana Singh and Rajesh Taneja, published by Avichal Publishing Company).

The first day ended with a free communications session with presentations of a wide variety of abstracts.

The second day of the conference opened with sessions revolving around a multidisciplinary approach. **Robert Moldwin** MD (USA) looked at the role of the urologist, emphasizing that the IC/BPS (UCPPS) population is large and clinically complex. While urologists and urogynecologists may remain the central caregivers, multifaceted/multidisciplinary care is needed but rarely applied. Many urologists/urogynecologists or urology departments simply do not have a direct line to other helpful subspecialists. They may also be too busy to identify other pain generators and may not even have any interest in chronic pain conditions, having been trained as surgeons. He suggested that specialized training and incorporation of medical urologists, primary care-urology specialists and nurse practitioners should be considered. Furthermore, guidelines need to be improved to incorporate this aspect, training programmes should be enhanced and specialized fellowships be developed. Centres of Excellence should consider Virtual versus Physical Structure.

**Jane Meijlink** discussed comorbidities/associated disorders noting that many patients with IC/BPS also have one or even multiple comorbid conditions, including potentially very disabling systemic autoimmune diseases. Comorbid conditions add greatly to the suffering of the IC/BPS patient and make treatment very complex, particularly in the case of systemic diseases. A multidisciplinary approach is therefore essential.

Associated disorders include allergy, irritable bowel syndrome, sensitive skin, vulvodynia, fibromyalgia, chronic fatigue syndrome, migraine, asthma, Crohn's disease/ulcerative colitis, rheumatoid arthritis, systemic lupus erythematosus and Sjögren's syndrome. Adverse reactions (intolerance) can occur without involvement of the immune system. Intolerance mainly occurs to food, drugs and chemicals. Non-allergic intolerance (particularly to drugs) may be occurring very frequently in our IC/BPS patients, but no data are available on the prevalence in IC/BPS. Multiple drug intolerance can cause great problems with treatment.

Sjögren's syndrome is one of the most common systemic autoimmune diseases, characterized by dry or irritated eyes and dry mouth, but all other organ systems can be affected in many patients. Debilitating fatigue is common.

Interstitial nephritis, often as part of systemic Sjogren's, may cause distal renal tubular acidosis (DRTA) and occurs in up to 50% of Sjögren's patients, usually in a mild form. DRTA causes metabolic acidosis and compensatory hyperventilation to correct the acidosis. More pronounced DRTA causes hypokalaemia (low blood potassium) due to increased loss of potassium by the kidneys into the urine, which may occur in flares. In an IC/BPS patient, this potassium concentration in the urine can cause extreme pain, urgency and frequency, particularly at night. While treatment with potassium citrate may correct both the acidosis and hypokalaemia on the blood side, the pain caused in the bladder is much more difficult but may be helped by instillations. There are no literature data on the prevalence of DRTA in IC/BPS, but it is likely to be due to an accompanying incomplete or complete Sjögren's syndrome.

Comorbidities should always be taken into account by the urologist and often make treatment very challenging and very individual. It's important to bear in mind that many systemic drugs used for other conditions can exacerbate and further damage the already compromised IC/BPS bladder.

It is a matter of great concern that rheumatologists today seem to know little if anything about IC/BPS, and it is clear that a big effort is needed to raise awareness in this group of doctors who treat many of our patients for rheumatic diseases.

Gastroenterologist **H. de Schepper** MD (Belgium) looked at IBS and bowel management, with an emphasis on diet, while **M.C. Gori** MD (Italy) spoke about the role of the psychologist and cognitive behavioural therapy.

**Kristene Whitmore** MD (USA) examined the role of the sexuologist and sexual dysfunction in IC/BPS, looking at both superficial (introital) and deep dyspareunia as well as vaginismus which is recurrent or persistent spasm of vaginal musculature that interferes with vaginal penetration. Investigations and imaging include: urodynamics, frequency volume chart, pad testing, ultrasound imaging, magnetic resonance imaging, pelvic floor manometry, dynamometry, electromyographic diagnosis, VAS and pain mapping.

Nurse consultant **Ria Pothoven** (NL) looked at the very important role the specialized IC/BPS nurse plays in the clinic, emphasizing the importance of winning the trust of the patient. Trust is very important in patients with a poorly understood chronic disease and crucial to make the treatment successful. Take your time to build up this trust, she said. The nurse spends more time with the patient than the urologist and this allows the patient to open up and tell his or her story in detail. Always keep listening to your patients. Specific aspects for the nurse to find out include: what is this patient's biggest issue? What is causing the patient the most bother? What does the patient expect or hope for from this visit? The approach is to find out how the best quality of life can be achieved for each individual patient? Shared decisions make your patient more motivated. Be pragmatic and creative in your approach. Work together with the entire clinical team to find the best solutions for each individual patient's problems.

Physiotherapist **Fetske Hogen Esch** (NL) stressed that well-trained pelvic physiotherapists should be part of a multidisciplinary approach in diagnosis and treatment of patients with IC/BPS. She considered that general knowledge of the peripheral nerves in the pelvic area is poor, while musculoskeletal causes of IC/BPS have not always been taken into account. Interventions used in clinical practice include familiarizing the patient with anatomy and physiology, toilet behaviour/bladder training, relaxation techniques and body awareness, breathing exercises, adjustment of posture, rehabilitation

of extra pelvic musculoskeletal abnormalities, pelvic floor muscle relaxation, myofascial physiotherapy, pain education, TENS/PTNS.

The practicalities of how to set up a multidisciplinary team were outlined by **Erik Arendsen MD**, urologist from the Andros/Gynos Clinic in the Netherlands. He explained that their method is aimed at creating a situation in which patients receive a diagnosis and treatment in a one-day appointment (one stop shop system) with a multi-disciplinary team, starting treatment immediately, if possible. This method starts with the nurse consultant who handles intake by phone before the appointment, the patient then sends the completed standard questionnaires to the nurse. At the appointment, the urologist takes a history, performs a cystoscopy and finally gives a diagnosis. Following this a check is carried out by a pelvic floor therapist. A gynaecologist then analyses the hormonal situation in the case of female patients, a dietician checks for allergies, bowel problems and gives dietary advice. The last part of the one-stop-appointment will be undertaken by the nurse again: performing PTNS, doing an instillation and teaching the patient how to do self-instillation at home, together with life-style advice.

If necessary, the team may advise patients to attend additional appointments, while various other disciplines could be consulted if required such as a sexologist, counsellor, gastroenterologist, neurologist or pain centre for example. But the patient will always stay under the supervision of the Clinic as the lead practitioner. The last meeting will be with the supervising urologist. Many treatment options are available which are applied according to the individual needs of an individual patient. These include urinary analgesics, medication, pain management, treatment of any existing infection, hormone suppletion, physical myofascial therapy, behavioural therapy, muscle relaxation, trigger point injections and focusing treatment on bladder training. But they can also provide e.g. neurostimulation, nerve blocking, botox on special indication, dietary advice and treatment of bowel problems.

All team members in the Clinic are especially focused on making life as normal as possible for the patient, restoring the activities of daily life, treating anxiety and depression (also, if necessary, with the help of a psychologist or counsellor) and most importantly individual care for each patient.

**Lori Birder MD (USA)**, Professor of Medicine, noted that increased oxidative stress, declining mitochondrial activity, along with autonomic dysfunction may be hallmarks of many chronic pain conditions. These changes can upregulate inflammatory factors that affect bladder structure and function. New strategies such as antioxidants that target specific mitochondrial pathways in the dysfunctional bladder may be useful in treating IC/BPS.

The urothelial GAG layer and IC/BPS were discussed by urologist **John Heesakkers MD (NL)**. He explained that there are 4 types of GAG:

- Heparins and Heparan sulfates: on most cell surfaces; receptors & modulators of proteins, bind (anti)thrombin.
- Chondroitin & dermatan sulfate: protect barriers.
- Hyaluronate: constituent of connective tissue.
- Keratan sulfate: sealant in cartilage & cornea.

Regarding the GAG layer in the bladder, he noted that the amount of proteoglycans in the bladder surface far exceeds that of normal tissue. There is also a low cell turnover compared to other tissue. And it is non-adherent for bacteria that attach to uroplakins. The urothelium is coated with a thick layer of proteoglycans glycoproteins. Impermeability can occur due to downregulation of proteoglycan synthesis due to viral infection or mediators in urine; through neutralization of surface charges by cationic proteins or genetic factors; or by improper signaling of repair. GAG replenishment therapy is only necessary when the GAG layer and urothelium are damaged. When the GAG layer is damaged, impermeability is impaired.

The microbiome is currently a healthcare hot topic and this naturally includes the urinary bladder. **Dick Janssen** MD (NL) talked about microbiome involvement in IC/BPS. The microbiome forms the connection between the human host and the external environment, he explained. Since 2000, genetic sequencing techniques have allowed us to identify previously unculturable bacteria. In 2008, the Human Microbiome Project was started to characterize microbiomes of different organs. The interesting part of the urinary tract microbiome is that the bladder and urine were for years considered to be sterile in a healthy situation, whereas today some 63 species of bacteria have been identified in the urine of healthy people. In IC/BPS there appears to be a reduction in the biodiversity of the microbiome. However, there is always the possibility that these patients may have received frequent antibiotic treatment. At present, no decisive pathogen or absence of benign bacteria have been found to explain the pathophysiology of BPS/IC. However, microbiome alterations are correlated to IC/BPS. Improvement in stratification and sampling could provide more clues. However, he emphasized that microbiome research is still at an early stage.

Researcher **Thomas Hoogeboom** (NL) looked at the problems currently faced by researchers when addressing alternative but adequate study designs for rare diseases that can convince coverage-decision-makers. This is particularly topical in the Netherlands where there is no approval for reimbursement of intravesical treatment and many trials are dogged by the placebo effect.

In a session of short abstract presentations by patient advocates, **Jane Meijlink**, IPBF, spoke on “An urgent case for sensory urgency”. This concerned a change in the definition of urgency back in 2002, which has not yet been reversed, when insertion of the word “sudden” made the term urgency exclusively applicable to overactive bladder. Officially, IC/BPS patients no longer had urgency, with far-reaching negative consequences for both patients and research since it led urologists and pharma to believe that IC/BPS patients do not suffer from urgency. Attention was consequently exclusively focused on pain.

These problems could be resolved by reintroducing the former term “sensory urgency”: a compelling need to urinate due to intolerable pain or other unpleasant hypersensitive sensation. Reinstatement of sensory urgency would ensure that the symptoms of the real patients do not continue to be misrepresented, and that research and drug development are based on the real-life disease and symptoms. The speaker therefore recommended to ESSIC that they bring back sensory urgency in any new ESSIC definition of this disease.

**Balaka Basu**, Founder of Interstitial Cystitis India (ICI), spoke on “Social Media – An Indian Perspective”, explaining how social media platforms proved to be a boon in creating and spreading awareness of IC/BPS throughout the vast continent of India and surrounding countries. This has been helped by the availability of cheap internet across India, wide usage of smart phones by Indians, popularity of social media platforms and last but not least a huge increase in the literacy rate in India. Social media is an excellent way to reach out to patients and the general public, to raise awareness, she explained. It enables you to reach millions of people very rapidly and is very cost effective. Social media platforms such as Skype or Zoom meetings have largely replaced traditional forms of support group meetings since travelling to a meeting is difficult for health reasons, distance, cost etc. Balaka explained that a call centre to help patients proved impossible due to logistical and financial constraints. Consequently, social media platforms such as WhatsApp and Facebook groups became effective instead. This can provide a listening ear round the clock. They use YouTube to focus on connecting experts to the patients, with interviews of experts in the field of IC/BPS and comorbidities uploaded to YouTube.

IC India has found that social media usage helps spread information faster, helps people connect better, does more jobs effectively with less cost and effort and makes the group go global rather than

stay local! However, Balaka stressed that traditional groups and meetings should not be replaced since many patients still feel comfortable with them and they help people to get to know each other personally. Online groups can be added along with the traditional groups so as to reach out to more patients and the general public. However, she emphasized that managing social media is a huge task and they are continually having to learn new techniques so as to be able to do it themselves.

**Gail Benshabat** gave a presentation about IC Support Canada, a new national support group for IC/BPS patients throughout Canada, founded by Gail Benshabat and Marnie Shainhouse. Patients face many challenges in Canada: finding a doctor, getting a diagnosis and until now support networks in Canada have been very limited. There is a lack of research and no data on how many people have the condition in Canada. The group is active on a Facebook Forum where group members share experiences, resources and support. Current activities include fundraising, communication and information, with webinars, interviews, podcasts, live events and a brochure. They have many new initiatives in the pipeline.

**Mathilde Scholtes**, Board Member ICP, the Dutch patient support group, presented the preliminary results of a patient survey aimed at better identifying patients' needs, improving awareness amongst clinicians, achieving more patient-centred clinical management and improving the public lobbying function. There were 234 respondents and results showed that IC/BPS has a severe impact on daily life, the highest impairment was related to sleep, and a poor outcome of general clinical care. It was evident that more attention needs to be paid to treatment of sleep disorders, social problems and work-related issues.

The last part of the meeting was devoted to three parallel workshops, an innovation at this ESSIC meeting.

**WORKSHOP 1** revolved around presentations from 5 new ESSIC Committees:

**Guideline Committee:** chaired by **Philip Hanno**, MD, (USA) who said we need a new international guideline sensitive to different healthcare systems and sensibilities. This should be a guideline that embraces new ideas from the past 5 years and which is easily updated in accordance with new developments and insights.

**Classification & Diagnostic Committee:** chaired by Mauro Cervigni, MD, (Italy), will work closely with the Guideline committee.

**Education Committee:** chaired by **Rajesh Taneja**, MD, (India). One focus will be to train urologists and urogynaecologists in IC/BPS and Hunner lesion.

**Scientific Committee:** chaired by **Jean-Jacques Wyndaele**, MD, (Belgium).

**Patient Advocacy Committee:** co-chaired by **Loredana Nasta** (Italy) and **Vicki Ratner** MD (USA)

When outlining plans for the Patient Advocacy Committee, Vicki Ratner looked at issues such as finding patient advocates, funding the new Patient Advocacy Committee, publicity, and also took a few minutes to mention the issue of now several reports of pigmentary maculopathy seen in long-term use of oral pentosan polysulphate sodium.

**WORKSHOP 2: PHYSIOTHERAPY** was chaired by **Jörgen Quaghebeur**, PhD, (Belgium) who explained that the pelvic floor has a complex innervation. A good pelvic floor function is important for pelvic girdle stability, continence, voiding/defecation, sexual function and delivery. Pelvic floor muscle assessment involves an evaluation of the PFM muscle function, tone, pain, injury. The treatment of pelvic floor dysfunction mainly consists of manual revalidation, stimulation techniques or relaxation. He stressed that we need a thorough clinical assessment in a systematic way showing indications for intervention and treating the symptoms, a multidisciplinary approach, and experts trained to deal with the problem.



**Marijke Slieker-ten Hove**, PhD, (NL) looked at relaxation therapy in patients with bladder pain symptoms, noting that when making the diagnosis both physical and mental aspects are very important. Relaxation therapies are an important instrument in the treatment: mindfulness-based stress reduction. However, existing studies were not able to define the best approach for the treatment of BPS/IC. The lack of standardized treatment may be related to the diversity of interventions used; therefore, further studies with better methodological quality are needed.

**Joelle Roenen** (NL) discussed electrostimulation, emphasizing that a multidisciplinary approach is needed treating patients with chronic pelvic pain. In the pelvis different systems exist that influence each other (e.g. organs, arteries, veins, nerves, lymphatic vessels, fasciae, muscles). Treating patients with chronic pelvic pain is often a long, difficult process. Sometimes the results of therapy are frustrating for both the patient and therapist. An extensive anamnesis, explanation concerning pain physiology, observation, manual evaluation, are part of the treatment. Electrostimulation techniques can be necessary when treating CPPS.

**Alexandra Vermandel**, PhD, (Belgium) talked about genito pelvic pain/ penetration disorder (GPPPD), noting that extreme discomfort or pain while experiencing or attempting intercourse can reduce sexual desire, disrupt relationships, and leave a woman feeling less feminine. It also can lead to frustration and unhappiness of the partner. Treatment includes education, pelvic floor physiotherapy, medical interventions and surgical interventions, though sexual function may be optimized through a multifaceted approach. The disorder involves difficulty having intercourse and feeling significant pain upon penetration. GPPPD is often correlated with pelvic muscle tension. Pelvic floor therapists are the optimal provider to treat this condition.

**WORKSHOP 3** was a hands-on nursing workshop chaired by **Sandor Lovasz**, MD, (Hungary) and **Ria Pothoven**, nurse consultant (NL), looking at the role of the nurse specializing in IC/BPS, bladder instillations and preparing the products, and catheterization versus use of the new catheter-replacing adapter from Hungary which is proving popular with patients. Ria Pothoven looked at the role of Percutaneous Tibial NeuroStimulation (PTNS) and TENS.

This session was followed by a lively summing up by **Dick Janssen** with a number of take-home messages.

IC/BPS patients should be treated with a multidisciplinary team to provide the best care, also making use of anaesthiologist/pain specialist, gastroenterologist, gynaecologist and rheumatologist. While there is heterogeneity in the disease, there is also heterogeneity between guidelines. Basic science gives us interesting clues about GAGs, mast cells and novel neuromodulation techniques. There is more than a standard RCT in clinical research. We should explore and adopt sensible and feasible research methodologies to try to increase the number of successful trials. It is important to incorporate patients and their organizations in research and listen to them to improve our healthcare. Training of clinicians is needed to produce more IC/BPS experts.

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