“The absence of evidence for chronic pain does not imply the absence of pain.” (Dr Thibault Riant)

Following the success of the 1st WCAPP in Amsterdam in 2013, this second multidisciplinary World Congress on Abdominal & Pelvic Pain was organized in Nice, France by Convergences in PelviPerineal Pain (Convergences PP), a federation of different French scientific societies concerned with chronic pelvic perineal pain, in collaboration with the Abdominal and Pelvic Pain (AAP) special interest group (SIG) of the International Association for the Study of Pain (IASP), the International Pelvic Pain Society (IPPS). The International Pelvic Pain Partnership (IPPP), a patient alliance, also participated and organized a parallel patient workshop on one day of the conference, along with many French patient organizations. WCAPP was organized parallel to the meeting of the International Urogynaecological Association (IUGA) with a half-day shared session. The theme of the conference was to endeavour to understand how patients can suffer often extreme levels of pain with no visible abnormalities on the basis of standard tests (clinical, bacteriological, endoscopic imaging) or with minor lesions that are disproportionate to the symptoms and to examine how this pain can be legitimately treated with no available evidence base, in relation to interstitial cystitis/bladder pain syndrome, chronic prostatitis, endometriosis, pelvic congestion, vulvodynia, irritable bowel syndrome, proctalgia fugax, adhesions, chronic pelvic pain, pudendal nerve pain, musculoskeletal dysfunction, low back pain and the issue of central sensitization.

Scientific Programme: highlights

Key messages that echoed throughout the conference were:

1. The need for a multidisciplinary approach;
2. Look at the whole patient, holistic approach, while at the same time phenotyping;
3. The need for personalized treatment, as every patient is different;
4. The aim of treatment is to improve quality of life for the patient.

A key question heard throughout this meeting was: why do a few patients have only one pain syndrome, while other may have multiple pain disorders? What makes these patients different?

Visceral sensitivity

Dr Ursula Wesselman, Professor of anaesthesiology, neurology and psychology in Birmingham, Alabama, USA, opened the first session on lesion and dysfunction with her presentation on visceral sensitivity. She explained that abdominal and pelvic pain conditions are conditions of visceral hypersensitivity. The viscera are minimally sensate and we normally do not feel our visceral organs. While visceral pain is the most frequent form of pain, few (if any) medications have been specifically developed for the treatment of chronic visceral pain. Furthermore, patients are often seen by medical practitioners who have limited experience in treating chronic visceral pain since this topic is
rarely addressed in medical training. She also noted that the recognition of chronic abdominal and pelvic pain as a “chronic pain syndrome” is fairly new in the clinical subspecialties of urology, gynaecology and gastroenterology. Most pathophysiological research studies have focused on models of cutaneous or neuropathic pain. However, the clinical presentation of visceral pain is different from cutaneous and neuropathic pain.

Dr Wesselman emphasized that doctors should keep the global picture in mind rather than chasing a single symptom! Chronic pelvic pain is often associated with other pains. The same patient may have multiple urological, gynaecological and gastrointestinal pain. There may also be pain elsewhere e.g. headache, chest pain, joint pains).

The speaker emphasized that phenotyping of patients with pelvic pain syndromes allows subgroups to be identified which could potentially be targeted for specific types of treatment based on the underlying pathophysiological mechanisms.

A key point to note is that the presence of multiple functional somatic syndromes including chronic visceral pain syndromes are risk factors for surgery (see Hysterectomy in early BPS/IC; Warren et al. 2014). Dr Wesselman stressed that until further populations have been assessed in prospective research studies, patients who are contemplating hysterectomy for pain and who additionally have IBS or multiple functional somatic syndromes should first consider alternative therapies.

She also explained that studies have shown that lifestyle modifications can influence visceral sensitivity.

She raised a number of questions including: why do some patients develop only one pain syndrome, but never other chronic pain syndromes. And this is certainly something that puzzles us in the IC/BPS world: some IC patients have multiple comorbidities yet others are adamant that they have nothing other than their bladder problem. Another question; is it possible to predict which patients will be at risk to develop other chronic pain syndromes? And are there strategies for early intervention, preventing the development of other chronic pain syndromes? And what is the temporal relationship of the development of different pain syndromes in patients with chronic abdominal and pelvic pain?

This was an excellent, thought-provoking presentation by Dr Wesselman which certainly made the whole conference worthwhile for me and was a fantastic start to the meeting.

On the subject of treatment: this is a field of medicine that is not yet evidence-based and patients may receive conflicting information from doctors. According to Dr B. Messelink, patients’ treatment tends to be fragmented as they are seeing different specialists, pulling the patient apart as it were, and nobody is managing the whole patient. This underlines the need for multidisciplinarity and transdisciplinarity. Look at the whole patient while at the same time phenotyping. This means a detailed medical history and the use of questionnaires can be useful for information since there is usually insufficient time during g appointments for the patient to tell the doctor everything.

**Chronic perineal pain and pudendal neuralgia**

Being in France at a conference organized by Convergences-PP, we were of course looking forward to hearing about the latest insights from Nantes Pelvic Pain Centre and other centres into chronic perineal pain and pudendal neuralgia. Dr Stephane Ploteau from Nantes looked at anatomy, and the anatomic variations of the nerves including the pudendal nerve which is not necessarily located in the same place in each individual patient. The nerves may have different pathways and also be of different sizes. This variation has implications for sacrospinous colpopexy (to repair prolapse), pudendal nerve blocks (pain or anaesthesia), neurolysis in the setting of nerve entrapment,
neurostimulation of the pudendal nerve and understanding of the mechanisms of pain. Knowledge of anatomy and these variations is essential to avoid damaging the nerve and to treat pain.

Dr Jean-Jacques Labat from Nantes took us through the Nantes criteria for the diagnosis of pudendal neuralgia by pudendal nerve entrapment (PNE) and it is perhaps worth repeating them here in brief:

- Pain in the territory of the pudendal nerve (from the anus to the penis or clitoris)
- Pain predominantly experienced while sitting (relief of pain when sitting on a toilet)
- Usually the pain does not wake the patient at night
- Pain with no objective sensory impairment
- Pain relieved by diagnostic pudendal nerve block.

**Four exclusion criteria:**
- Exclusively coccygeal, gluteal, pubic or hypogastric pain
- Pruritus
- Exclusively paroxysmal pain
- Imaging abnormalities able to explain the pain

**Other clinical signs of PNE**
- Gradual worsening during the day
- Neuropathic expression:
  - Somatic: burning, stinging, tingling, electric shocks, pins and needles, numbness, allodynia
  - Vegetative: rectal or vaginal foreign body sensation


Dr Labat emphasized that PNE is not the only cause of perineal pain. Inferior cluneal neuralgia is a new entity.

**Vulvodynia**

On the topic of vulvodynia, Dr Micheline Moyal-Barracco from Paris noted that many patients are not seeking medical advice due to the taboo aspects of vulvar conditions. She emphasized that more precise recommendation are needed for identification of neurological lesions and myofascial abnormalities responsible for vulvar pain. We need to know more about different subsets and different mechanisms and prognosis factors are needed in the classification of vulvodynia (primary versus secondary, associated pain comorbidities etc). Dr Ulrika Johannesson from Stockholm listed other pain disorders that vulvodynia patients may suffer from including tension headache, gastritis, irritable bowel syndrome, muscle pain, backache, fibromyalgia, temporomandibular dysfunction, urethral/bladder pain. On the subject of treatment, Dr Giao Do-Pham, emphasizing that the multidisciplinary approach is needed, mentioned topic local anaesthetics, emollients and oestrogens; physiotherapy; treatment of superinfections (candida); information and education; psychotherapy and sexotherapy. She reviewed studies on the subject of treatment.

Pharmacological interventions include:
- **Topical:** local anaesthetics, gabapentine/amitriptyline
- **Regional:** regional anaesthetics, botulinum toxin
- **Systemic:** anticonvulsants, and other such as antifungal, interferon, NSAIDs etc
Non-pharmacological interventions include:
Information
Regional interventions: physiotherapy, TENS
General interventions: education, acupuncture, cognitive behavioural therapy.

However, she concluded from the studies that there is no high evidence for a specific approach but that treatment should be based on an empirical and multidisciplinary approach.

Dr Giao Do-Pham was critical of definitions and classification: definitions are not always clear and classifications use many different terms.

A session on abdominal pelvic pain included presentations on endometriosis and adhesions, pelvic congestion syndrome and pelvic varicose veins. Dr Katy Vincent from the UK noted that since chronic pain is multifactorial, there is a need to focus on the patient and not just the pathology. Pathology should be looked for and treated, but other factors considered and treated simultaneously. Education is needed for gynaecologists, primary care and of course patients. What is needed most of all is evidence!

Dr Vincent asked “What do patients with chronic pelvic pain want?” and summarized this as:
- personal care
- to feel understood and taken seriously
- explanation as much as cure
- to be reassured.

Dr Jerome Rigaud from Nantes discussed visceral hypersensitivity which he described as:
- lower sensitivity pain thresholds
- functional disorders
- absence of organic causes

He divided bladder pain syndrome into: Bladder Pain Syndrome with abnormal cystoscopy (“pathological bladder wall” or cystopathy) and Bladder Pain Syndrome with normal cystoscopy (“hypersensitivity”).

The big question is, he said, is it the pain expressed by the organ or is it the organ that expresses the pain? In other words: is it a pain or an organ dysfunction? The concept of organ pain has been transformed into pain perceived in one or more organs.

He too emphasized that every patient is different so treatment has to be tailored to each patient.

Dr JJ Labat looked at visceral sensitization which he classified as follows:
- Bladder hypersensitivity: painful bladder syndrome without cystoscopic abnormalities
- Digestive hypersensitivity: irritable bowel syndrome
- Sexual hypersensitivity cause of vulvodynia, dyspareunia.

Dr Labat emphasized that pain is an emotion. The pain is not visible, but can be analyzed.

We also heard about the role of the physiotherapist from Maeve Whelan. Physiotherapy is recommended as a first line of treatment for the patient with chronic pelvic pain. Manual therapy is effective in some patients and should be used in conjunction with other psychological therapies. Postural correction, musculoskeletal correction and education are integral. Skilled physiotherapy assessment may help uncover specific findings.
Dr Alain Watier urged health providers to establish a positive patient-physician relationship. He said that the suffering from chronic pelvic pain is an emotional toll not only on the patient but also the family and healthcare providers. He concluded that chronic pain is the absence of pleasure and the best treatment for pain, whatever it may be, is to enable patients to experience pleasure in their lives once again.

Dr John Hughes, pain consultant from the UK, looked at the role of diagnostic blocks and concluded that it is not as easy as it looks. There are multiple variables influencing outcome. The research base is weak and further research is urgently needed to define the benefits. He concluded that clinically there feels like a role for these blocks and we need to develop a proper understanding of the role of diagnostic blocks.

**Surgery risks for hypersensitivity patients**

On the subject of surgery for chronic pelvic pain patients: it was emphasized that surgeons must take into account all comorbidities and all pain syndromes before taking any decision to carry out surgery. It is vital to assess which patients may be at risk for post-operative pain. It was noted that all surgery is bad for patients with hypersensitivity disorders.

**Patient workshop**

A workshop was held for patients all day on Friday 12 June on the theme of patient and professional perspectives of chronic pelvic pain. The aim was to facilitate discussion between chronic pelvic pain patients and support groups representatives and health professionals specialising in chronic pelvic pain. The main focus of this year’s workshop was to explore outcomes for chronic pelvic pain in treatment and self-management, but also for research. The day concluded with two presentations on standardisation and classification of chronic pelvic pain, emphasising how important it is for patient advocates and support groups to get involved in standardisation and guideline committees and all decision-making in the field of terminology, definitions and criteria.

**Convergences-PP next meeting**

A Meeting of Convergences-PP will be held in Aix-en-Provence, 15/16/17 September 2016.