W10: Rethinking Pelvic Pain: How to be a Hero
Workshop Chair: Charles Argoff, United States
03 September 2019 11:30 - 13:00

Start	End	Topic	Speakers
11:30	11:40	Introduction, Distribution of Practical Clinical Materials, and Solicitation of Audience Needs Rejecting the organ-based approach	Charles Argoff Christopher Payne
11:40	11:55	Women: Causes of Localized Pelvic Pain with Treatments Pearls	Elise De
11:55	12:10	Men: If it's not Prostatitis, can you handle the truth?	Jeannette Potts
12:10	12:20	Questions for panelists, audience input	Christopher Payne
12:20	12:45	Small Fiber Polyneuropathy and Central Sensitization: how do these concepts apply to UCPP?	Charles Argoff
12:45	12:50	Assembling a Multidisciplinary Team and Using an Individualized Treatment Map versus One Page Timeline	Elise De
12:50	13:00	Comments and Questions	Charles Argoff Elise De Christopher Payne Jeannette Potts

Aims of Workshop
This workshop aims to provide concrete tools for everyday practice to simplify evaluation and treatment of patients with Chronic Pelvic Pain. The differential diagnosis of etiology and treatment algorithms will be presented. Clinical materials (patient educational material and questionnaires) will be shared.

Learning Objectives
1. Differential diagnosis for causes of pelvic pain
2. What to try first and what not to miss
3. Associated conditions – signs of systemic etiology and how to approach

Target Audience
Urology, Urogynaecology, PT, General Practice, Neurology, Colorectal, Conservative Management

Advanced/Basic
Intermediate

Suggested Learning before Workshop Attendance
- A Standard for Terminology in Chronic Pelvic Pain Syndromes: A Report From the Chronic Pelvic Pain Working Group of the International Continence Society. Neurourology and Urodynamics. Neurourology and Urodynamics DOI 10.1002/nau
- Pain Practice, Volume 12, Issue 2, 2012 111–141. Chronic Female Pelvic Pain – Part 2: Differential Diagnosis and Management.
- https://www.urotoday.com/video-lectures/bladder-health/video/mediaitem/788-embedded-media2017-07-05- 16-32-47.html
- https://www.urotoday.com/categories-media/1910-centers-of-excellence/bladder-health-coe/1029-embedde d-media2018-09-18-15-53-44.html
- Potts JM, Payne CK. Urologic chronic pelvic pain. Pain. 2012 Apr;153(4):755-8.
- Pain Med. 2016 Aug;17(8):1569-71. doi: 10.1093/pm/pnw001. Epub 2016 Feb 18. Presence of Decreased Intraepidermal Nerve Fiber Density Consistent with Small Fiber Neuropathy in Patients with Central Post-Stroke Pain. Cavalier Y[1], Albrecht PJ[2], Amory C[1], Bernardini GL[3], Argoff CE[1].

- Albrecht PJ, Hou Q, Argoff CE, et al. Excessive peptidergic sensory innervation of cutaneous arteriole-venule shunts (AVS) in the palmar glabrous skin of fibromyalgia patients: Implications for widespread deep tissue pain and fatigue. Pain Med 2013;14(6):895–915.
- Chen A, De EJB, Argoff C. Small-fiber polyneuropathy: implications for etiology and management of complex chronic pelvic pain. International Urogynecologic Association (IUGA) Newsletter. 12 (3) pp 10-11. Sept 2017.
- JAMA. 2018 Aug 7;320(5):507-508. doi: 10.1001/jama.2018.6941. Opioids vs Nonopioids for Chronic Back, Hip, or Knee Pain. Covington E[1], Argoff C[2], Stanos SP[3].

Description:
An estimated 6-30% of people worldwide experience chronic pelvic pain (CPP). CPP is responsible for numerous surgical procedures, is a major risk factor for disability and depression and has a tremendous burden on society. CPPS patients have among the poorest QOL scores in chronic disease. In the United States, "chronic prostatitis" is the most common urologic diagnosis in men older than age 50 years and is the third most common diagnosis in men younger than age 50 years. The global prevalence estimated to be 8-14%. Pelvic pain is even more common in women, affecting 1 in 7 and prompting approximately 10% of all gynecological office visits. Because it predominately affects people aged 30-50 it causes great impact in the workplace and at home. Those suffering with CPP encounter difficulty in finding clinicians willing and capable of addressing this complex set of conditions contributing to the symptoms.

Competent clinical care includes the appropriate assessment and treatment of the clinical condition. CPP cannot be avoided in pelvic medicine and requires the necessary skills to perform an adequate assessment of the person. Acquiring a few basic skills and triage strategies will not only **allow patients to access much-needed help**, it will improve **provider satisfaction in the interaction**. This session will present the differential diagnosis and treatment pearls, reducing the gaps in current knowledge through teaching a multifactorial and interdisciplinary approach.

We must also acknowledge that CPPS is not a diagnosis. It is a broad designation to describe a constellation of symptoms which affect the genitalia and/or pelvis, and may or may not be associated with voiding, sexual, or bowel dysfunction. We contend (although this is not an official ICS position) it should no longer be considered a category within the NIH-NIDDK Prostatitis Classification system.

Even though CPPS is historically considered to be a urological disease, the diagnosis and the etiologies are found most often to be non-urological. Indeed, the differential diagnosis is broad and we must avoid oversimplifying the solution. (For example physiotherapy could be seen as the new ciprofloxacin, i.e., a prescription given without an exam or diagnosis to support the indication.)

There is no short-cut. Technology cannot replace the history, nor a thorough, methodical physical examination. Caregivers must remember to pause… this is a condition which requires
a paradigm-shift, away from the surgical interventional mentality. In other words, “Don’t just do something…stand there!” Avoid unnecessary tests. Avoid a shot gun approach to therapy. Avoid algorithms intended to promote speed, when instead, these extinguish efforts to listen or motivation to thoughtfully touch and palpate the person behind the pain. In Tango, we learn that elegance is the efficiency of movement. This elegance can only be achieved if steps are executed thoughtfully, consistently and without superfluous or wasteful movements. (From Potts, Tango, 2007). This approach may seem to take longer. However, when done properly, with care, we get it right the first time.

The truth is, the condition of CPPS, demands that we be the healers of persons, rather than data crunchers or technicians.

Key Learning Points:

1) CPP sometimes has a solitary treatable local cause, contrary to the "Pain Syndrome" paradigm, and clinicians who take care of pain should be aware of the full differential, both within and outside of their specialty.
2) However, gender-based conceptions of pathophysiology focused on specific pelvic organ causes have not led to great outcomes. This workshop presents a refreshing way of thinking about patients presenting with chronic pelvic pain that will encourage better clinical results.
3) A multifactorial approach to promoters of pain can optimize outcome early in the treatment relationship.
4) Chronic pelvic pain is often a pervasive entity associated with pain and dysfunction in multiple body systems including urologic, gastrointestinal, gynecologic, and neurologic. Studies demonstrate the person with CPP experiences an average of 2.4 other painful conditions such as migraine, fibromyalgia, irritable bowel syndrome and others.
5) Each patient must be understood as a unique person. Patients often suffer from overlapping conditions, previously known as Functional Somatic Syndromes (Potts, 2001) and today, more appropriately recognized as Central Sensitization, Small Fiber PolyNeuropathy, or an interplay between the two. "Central sensitization" is a concept of amplification pathways critical to the establishment and maintenance of CPPS. The pathophysiology of "Small fiber polyneuropathy"(SFPN) points to dysfunction of the small c-fibers, a-delta fibers, and postganglionic sympathetics in the periphery, as well as modulation of autonomic control.
6) If we accept that for many patients there is no quick fix nor simple algorithm, we can recognize and address multiple contributing factors, prioritizing impact and individualization of therapy. In truth, pelvic pain is a syndrome and pelvic pain patients present a wide variety of underlying issues. Neither algorithms nor routine use of sophisticated testing are effective in understanding and managing pelvic pain. What is needed are the ears, hands, heart and mind of skilled clinicians. Clinicians who practice by these truths, being knowledgeable about but also able to look beyond older single-organ concepts, will find the approach more effective. This workshop will employ a diagnostic menu then a case based approach to illustrate a comprehensive evaluation strategy that allows individualized treatment planning.

The Key Concept Challenges Are:

1. Chronic Pain Syndromes are often not specific diseases, they are syndromes in which patients present with similar symptoms but have different underlying causes.
2. Chronic Prostatitis/Chronic Pelvic Pain Syndrome is almost never e.g. "a prostate disorder"
3. True Interstitial Cystitis is a specific diagnosable and treatable bladder disease
4. Bladder Pain Syndrome is NOT a diagnosis; is rarely a true bladder disorder
5. Myofascial abnormalities are common in CPPS but treatment focused *solely* on these have produced disappointing outcomes.
6. Small Fiber Polyneuropathy and Central Sensitization can initiate and perpetuate CPPS and should be suspected in complex and refractory pelvic pain
7. Successful management of CPPS patients stems from a careful, thorough initial evaluation, an individualized multifaceted treatment plan, and frequent reassessments.

The Take Home Messages Are:

1. There is no one algorithm for evaluation or treatment of CPPS
2. Success in managing CPPS stems from understanding and phenotyping the patients.
3. In patients with refractory chronic pelvic pain, a large proportion will meet the criteria for central sensitization syndrome and small fiber polyneuropathy.
4. Essentially all patients with CPPS are treatable, and many are curable. Believe that your patient can get well.
5. Expect success with an individualized treatment map. If not successful, reassess the patient and revise the plan.

6. Although applying sophisticated testing to populations of CPPS is sometimes counterproductive, consider additional testing when patients do not respond initially, when it is not possible to identify the underlying etiologies, or when specific indications are present (e.g. hematuria).

Chair:
Charles Argoff, MD, Neurologist, United States
Charles E. Argoff, MD, is Professor of Neurology at Albany Medical College and Director of the Comprehensive Pain Center at Albany Medical Center in New York. He completed fellowship in developmental and metabolic neurology at the National Institutes of Health/National Institute of Neurological Disorders and Stroke (NIH/NINDS). Dr. Argoff is a member of the International Association for the Study of Pain, the American Academy of Pain Medicine, and the American Academy of Neurology, among other professional organizations. He serves on the editorial board of the *Clinical Journal of Pain*. He is co-editor of the Neuropathic Pain Section of *Pain Medicine*. He has written on many types of pain, including myofascial pain, spinal and radicular pain, and neuropathic pain. He is one of the editors of the textbook *Raj's Practical Management of Pain, Fourth Edition*. He has also published the third edition of *Pain Management Secrets*.

- Small Fiber Polyneuropathy Is Prevalent in Patients Experiencing Complex Chronic Pelvic Pain. Chen A, De E, Argoff C. Pain Med. 2018 Feb 13. doi: 10.1093/pm/pny001
- Small fiber neuropathies (SFN) result from damage to the peripheral nerves affecting small myelinated A-Delta and unmyelinated C fibers. The fibers affected include both small somatic as well as autonomic fibers Thermal perception and nociception are subserved by small nerve fibers. Enteric function is also subserved by small nerve fibers
- Large nerve fibers are heavily myelinated and involved in muscle control, as well as touch, vibration and position sense
- Most small fiber neuropathies occur in a length-dependent fashion – first stocking distribution changes and then later glove distribution. Less common but no longer rare, non-length dependent small fiber polyneuropathies can results in symptoms involving the face, trunk, proximal limbs, or other more localized areas, Muscle cramps may be one of the presenting complaints of SFN. Epidemiologic data from the Netherlands suggest a minimum incidence of 12/100,000 people. Children also can experience SFN-the diagnosis may be more challenging than in adults.
- Medical conditions associated with SFN include diabetes, impaired glucose tolerance, metabolic syndrome, sarcoidosis, thyroid dysfunction, HIV, vitamin B12 deficiency, vitamin B1 deficiency, chemotherapy, antiviral agents, celiac disease, Sjogren's Syndrome, paraneoplastic syndromes, paraprotenemia, rheumatoid arthritis, lupus, Guillain-Barre syndrome, CIDP, RLS, Hepatitis C, amyloidosis, Fabry's Disease, EDS, Hereditary neuropathies, central post stroke pain, Ethanol use, post vaccination, sodium channelopathies, and idiopathic.
- Symptoms vary widely in severity. Often affected individuals describe a gradual onset of vague distal sensory disturbances. Examples include feeling like there is sand in the person's shoe, a sock feeling as if it has pebbles in it, pins and needle sensations, cold painful sensations or tingling. Burning pain in the extremities, sometimes severe are common as are allodynia and hyperesthesia. Socks or bedsheets may be painf and symptoms are often worse at night. Autonomic and enteric dysfunction including: dry eyes, dry mouth, lightheadedness with changes in posture, syncope, abnormalities of sweating, erectile dysfunction, GI symptoms such as nausea and emesis, constipation, diarrhea, changes in urinary frequency including nocturia.
- Skin Biopsy- this has become widely accepted as a technique to evaluate the structure of small nerve fibers. The standard is a 3-mm skin punch biopsy that can be taken from anywhere over the body. The

results are expressed as the number of intraepidermal fibers per mm. The sensitivity (78-92%) and specificity (65-90%) is fairly high for this technique. Intraepidermal nerve fibers (IENF) are unmyelinated sensory endings that arise from the sub-papillary dermis. They widely express the TRPV1 receptor- this means they are distal nociceptors

- Using antibodies against the protein gene product (PGP 9.5), a cytoplasmic ubiquitin carboxyl-terminal hydrolase, the number of fibers crossing the dermal-epidermal junction can be quantified – measured as IENF/millimeter.
- What about complex pelvic pain? A recently published retrospective study's objective was to demonstrate the prevalence of SFN in patients with refractory chronic pelvic pain. 25/39 patients (64%) demonstrated skin biopsy findings consistent with SFN
- Co-morbid conditions noted included GERD (46%), migraine (38%), IBS (33%), fibromyalgia (38%), endometriosis (15%), interstitial cystitis (18%), vulvodynia (5%), other chronic pain syndromes (36%). What does this mean?

Speakers:

Jeannette Potts, MD, General Practitioner, United States

Medical Doctor with Residency Training in Family Medicine followed by fellowship in Urology. 15 years as faculty in Cleveland Clinic Urology Co-Founder Vista Urology and Pelvic Pain Partners. Investigator in NIH CPPS Clinical Trial Group. Course Director Annual AUA meeting since 2012 Accomplished speaker-presented over 100 international lectures.

- Potts JM. Male Pelvic Pain: Beyond Urology and Chronic Prostatitis. Curr Rheumatol Rev. 2016;12(1):27-39.
- Potts JM, Payne CK. Urologic chronic pelvic pain. Pain. 2012 Apr;153(4):755-8.
- Potts, Tango:Lessons for Life. CCF Press, 2007.
- FitzGerald MP, Anderson RU, Potts J, Payne CK, et. al.; UCCRN. Randomized multicenter feasibility trial of myofascial physical therapy for the treatment of urological chronic pelvic pain syndromes. J Urol. 2009 Aug;182(2):570-80.
    - Potts: Chronic pelvic pain syndrome: a non-prostatocentric perspective. World J Urol 21: 54-56, 2003.
    - Potts: Prostatitis; Alternative approaches: biofeedback, progressive relaxation and the concept of functional somatic syndromes. European Urol, Suppl, March, 2003.

Christopher Payne, MD, Urologist, United States

Medical Doctor with Residency in Urology and Fellowship in Female Urology. Emeritus Professor of Urology, Stanford University. Co-Founder, Vista Urology & Pelvic Pain Partners. Principal Investigator on two NIH grants for collaborative clinical research in Urological Pelvic Pain. Extensive speaking experience--prior AUA and ICS Course Director.

- Payne CK. A New Approach to Urologic Chronic Pelvic Pain Syndromes: Applying Oncologic Principles to "Benign" Conditions. Current Bladder Dysfunction Reports. March 2015;10(1), pp 81-86.
- 66. FitzGerald MP, Payne CK, Lukacz ES, et. al.; ICCRN. Randomized Multicenter Clinical Trial of Myofascial Physical Therapy in Women with Interstitial Cystitis/Painful Bladder Syndrome and Pelvic Floor Tenderness, J Urol 2012 June;187(6):2113-2118.
- Potts JM and Payne CK: Urologic Chronic Pelvic Pain. Pain. 2012 Apr;153(4):755-8.

Elise De, MD Urologist, United States

Dr. Elise De specializes in Female Pelvic Medicine and Reconstructive Surgery within the Department of Urology at Massachusetts General Hospital - Harvard Medical School in Boston MA. Her clinical practice is composed of incontinence, prolapse, neurogenic bladder, pain and voiding dysfunction in men and women. She has spoken at meetings throughout the societies nationally and internationally. Her current research includes systems of care in

pelvic floor disorders. She cofounded the Albany Pelvic Health Center, a multidisciplinary navigated system caring for people with pelvic pain, and now collaborates within the Center for Pelvic Floor Disorders at Massachusetts General Hospital.

- Chen A, De EJB, Argoff C. Small-fiber polyneuropathy: implications for etiology and management of complex chronic pelvic pain. International Urogynecologic Association (IUGA) Newsletter. 12 (3) pp 10-11. Sept 2017.
- Ulmer WD, Gilbert JL, De E. Urethritis in women—considerations beyond urinary tract infection. Current Bladder Dysfunction Reports. 2014; 9(3): 181-187. DOI 10.1007/s11884-014-0246-7.
- Dobberfuhl AD, Spettel S, Schuler C, Dubin AH, Levin RM, De EJ. A novel cystometric model of pelvic floor dysfunction after rabbit pelvic floor noxious electrical stimulation. Female Pelvic Med Reconstr Surg. 2016 Jul-Aug;22(4):248-253. PMID: 26829345