Additional Q&A for ERN eUROGEN Webinar 86: How I diagnose Interstitial Cystitis & Bladder Pain Syndrome – the ESSIC view

Question: How many years are needed to get a correct diagnosis respect the onset of symptoms in your country?

Prof. Zaitcev: Unfortunately, on average, 3-5 years

Prof. Akiyama: Not having the robust data, but approximately it passes through 2-3 years with 3 clinics to reach out the correct diagnosis of IC/BPS with IC/BPS expert urologists in Japan.

Question: I have been hearing for over a decade talk about the phenotyping and many projects in the US have been dedicated to this topic. The question is if, in your practice clinic, the phenotyping influences your approaches or therapies for IC patients?

Prof. Zaitcev: BPS is a heterogeneous syndrome rather than a specific disease which would explain the failure of "one size fits all" therapy. We use in our clinical practice the original UPOINT algorithm the urinary domains (U), psycho-social (P), organspecific (O), infection (I), neurological (N), muscle tension and tenderness (T). Each domain is diagnosed clinically and is associated with specific therapies. This approach has proven effective for patients even after many years of failed therapies.

Prof. Akiyama: It does. Proper phenotyping is mandatory to make the optimal treatment strategy on a subtypic basis since IC/BPS with and without Hunner lesions are totally different diseases with different etiologies.

Question: "When do you indicate a radical solution (cystectomy) in patients with primary chronic bladder pain syndrome? And does it make sense if the pain is already centralized?

Prof. Akiyama: Not radical, but simple total cystectomy or partial cystectomy with bladder augmentation should be implemented for patients with Hunner lesions whose bladders have been completely contracted accompanied by VUR and hydronephrosis. Cx should not be performed for patients with BPS (i.e., not having the lesions).

Question: Can you share your experience with IC in male patients? Should we perform cystoscopy to every man with frequent and urgent symptoms?

Prof. Akiyama: Regardless of the gender, cystoscopy should be performed whenever patients are suspected of having IC/BPS, i.e., complaining bladder/urethral pain related to lower urinary tract symptoms such as urinary frequency and urgency, without obvious bladder diseases (bladder stone, malignancy, chemical cystitis, radiation cystitis, etc) Pain is the most cardinal symptom characteristic of IC/BPS.