

**REVIEW OF THE EUROPEAN ASSOCIATION OF UROLOGY (EAU)
ANNUAL CONGRESS 2018
16-20 MARCH 2018, COPENHAGEN, DENMARK**

**European Reference Networks – EAU Patient Information – OAB Phenotyping
- New catheter-replacement adaptor device presented at EAU**

The 33rd annual congress of the European Association of Urology was held this year in Copenhagen, Denmark. While there has been a noticeable decline in interest in recent years at the EAU annual congress in chronic urogenital pain such as IC/BPS and hypersensitive bladder, Sunday 18th March did include several sessions of some interest to our field, while the Lovasz syringe adaptor for intravesical instillation attracted much attention.

**UROLOGICAL SYRINGE ADAPTOR – MINIMALLY INVASIVE DEVICE FOR
INTRAVESICAL INSTILLATION**

This ingenious urological syringe adaptor device, known as the MID-ii[®] and the brainchild of IC/BPS expert Dr Sandor Lovasz from Budapest, can potentially revolutionize bladder instillation and serve as a catheter replacement in many IC/BPS patients. It avoids damage to the sensitive tissue lining the urethra and provides an ideal way of treating the urethra which is normally difficult to achieve with a catheter. Use of the adaptor was demonstrated by Dr Lovasz himself in the exhibition during the EAU congress and attracted considerable interest.

ERN EUROGEN SESSION www.eurogen-ern.eu

This was a specialty session for the European Reference Network (ERN) for Rare and Complex Urogenital Diseases and Conditions and eUROGEN. Information about ERNs in general can be found at https://ec.europa.eu/health/ern/overview_en.

eUROGEN is one of the European Reference Networks (ERNs), with 29 active units in 11 EU member states, approved and supported by the European Commission and coordinated by the EAU. The network coordinator is Professor Christopher Chapple, with Michelle Battye as eUrogen manager and EAU EU policy coordinator. eUROGEN is specifically for patients with rare and/or challenging or complex urogenital diseases or conditions which need highly specialised assessment and surgery. If you take a look at <http://eurogen-ern.eu/about-us/organisational-structure/> you will see that IC has been added to the list under workstream 2 under functional urogenital conditions.

This is a new form of cooperation across Europe, using a new IT platform and toolbox with collaboration on clinical guidelines, research & innovation knowledge, generating and sharing evidence, training and e-learning. The aim is to achieve real improvement in care for patients with rare or challenging conditions. When these patients cannot be adequately treated in their own country their case can be referred to an ERN to be dealt with using a new IT platform, the Clinical Patient Management System (CPMS). This allows virtual multi-disciplinary team meetings, so that the expertise travels across borders rather than the patient. The platform launched in November 2017 and eUROGEN already leads as its top user.

EURORDIS – the European Organisation for Rare Diseases – is a key partner in this venture and works with the Commission Expert Group on Rare Diseases, clinical leads and patient representatives to

ensure that every rare disease patient has a home within the ERN system. See: <https://www.eurordis.org/content/about-european-reference-networks>. Patients and their organisations can become ePAG members. Read about the role of ePAGs: <https://www.eurordis.org/content/epags>

According to Michelle Battye, eUrogen aims to deliver: quicker specialist evaluation, more equitable access to quality diagnosis, treatment and care for patients and highly specialized assessment and surgery in order to improve care for patients with rare or low prevalence complex diseases or conditions, to concentrate expertise where capacity and knowledge are rare, to help patients and health professionals know where to find expertise for the diagnosis and treatment of certain conditions, as far as possible, expertise to travel across borders, not the patient and to act as focal point for medical training and research.

Each eUROGEN workstream was represented in the session: Dr. Fred Van der Toorn (NL) spoke on Hypospadias registries and clinical implications (WS1: Rare congenital uro-recto-genital anomalies); Dr. John Heesakkers (NL) spoke on Complex functional urology; research, knowledge, gaps and solutions (WS2: Functional urogenital conditions requiring highly specialized surgery); and Prof. Maarten Albersen (BE) spoke on Clinical aspects and ERN impact on penile tumour care improvement (WS3: Rare urogenital tumours).

A presentation on the ERN Patient Perspective was given during this session by Serena Bartezzi, from the Italian IC patient association (AICI) and eUROGEN ePAG representative. "Patient, clinicians and researchers' collaboration will be the deciding factor of the success of the RRNs", she said. At the moment, only two patients are working in eUROGEN, Serena Bartezzi and Dalia Aminoff, both from Italy. Patients have had a huge part to play in making ERNs a reality and are involved in eUROGEN at every level, advising on strategy, disease specific areas, pathways, guidelines, and patient information. Serena Bartezzi emphasized the role for patient groups in ERNs: "If you involve us we can really make the difference, as we can advise you what a disease means for patients."

EAU PATIENT INFORMATION SESSION

The EAU now has its own patient information section at <http://patients.uroweb.org/>, albeit limited at the moment and no sign of patient information on IC/BPS yet. The main purpose of this website is to provide patients with reliable, unbiased, comprehensive, clear information in urology. It should be good quality but easily read and understood. However, one of the speakers in this session emphasized that patients must be involved in developing the information. While this session largely focused on cancer, a particularly interesting presentation by Dr M.R. van Balken concerned health illiteracy and the taboo that rests on this. Many patients will not admit that they cannot read. Furthermore, Europe, with its waves of migrants, has many people who have little or no knowledge of the host language, while at the same time huge variations in levels of literacy and education mean that information produced for one group may be incomprehensible to another. This emphasizes that however much information (or symptom scores) we all produce, it is of no use if patients can neither read nor understand it.

PLENARY SESSION 4: CONTEMPORARY STORAGE LOWER URINARY TRACT SYMPTOMS MANAGEMENT

- Pathophysiology of non-neurogenic OAB: rather multifactorial than idiopathic syndrome, presented by Dr Benoit Peyronnet

Bearing in mind that the IC/BPS and hypersensitive bladder world is currently focusing much attention on how to get realistic phenotyping off the ground, it was particularly interesting to hear Dr Benoit Peyronnet of Rennes University Hospital, France putting forward a suggestion in this session as to how overactive bladder (OAB) could potentially be phenotyped. The problems surrounding OAB are indeed somewhat similar to the problems with IC/BPS, since in the case of both “syndromes” patients with similar symptoms but not necessarily the same conditions or diseases have been lumped together rather indiscriminately. In both cases, this has made treatment difficult and mainly a question of trial and error.

His presentation put forward new ideas for possible phenotyping of OAB, with the aim of improving treatment. He noted that the idea of “One size fits all” has its limitations in OAB. Many patients stop their medication because it simply doesn’t work. All very familiar to us in the IC/BPS world where individualized treatment is the only answer.

The speaker suggested possibly isolating some 11 OAB phenotypes although there may be more or may be less. He noted that it is obvious that all these different phenotypes cannot be equally addressed by each treatment and that some therapeutic options may be more effective with some phenotypes. And he explained that he would go into much more detail in the full paper when published.

The International Painful Bladder Foundation does not engage in the practice of medicine. It is not a medical authority, nor does it claim to have medical knowledge. Information provided in IPBF emails, newsletters, patient information and website is not medical advice. The IPBF recommends patients to consult their own physician before undergoing any course of treatment or medication.

While the IPBF endeavours to ensure that all information it provides is correct and accurate, it does not accept any liability for errors or inaccuracies.

© 2018 International Painful Bladder Foundation