USEFUL LINKS

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(See also Information for Professionals)

PROFESSIONAL, DEDICATED IC/BPS SOCIETIES

International Society for the Study of Bladder Pain Syndrome (ESSIC)
- Annual ESSIC Meeting

Society of Interstitial Cystitis of Japan (SICJ)
- Japanese guideline for diagnosis and treatment of interstitial cystitis
- Annual Meeting
- International Consultation on Interstitial Cystitis Japan (ICICJ)

East Asian IC Study Group

Global Interstitial Cystitis, Bladder Pain Society (GIBS)
- Annual Congress India

OTHER RELATED PROFESSIONAL ORGANISATIONS

International Continence Society
Multidisciplinary society for urologists, uro-gynaecologists, physiotherapists, nurses, basic scientists and researchers as well as patient advocates, with a focus on continence and pelvic floor disorders and pain.
- Annual ICS conference.
- Standardisation and guidelines.

European Association of Urology (EAU)
- Annual EAU Congress
- EAU Guidelines – Chronic Pelvic Pain
- Journal: European Urology

American Urological Association (AUA)
- Annual AUA Meeting
- Guidelines – IC/BPS
- Journal: The Journal of Urology

Society of Urodynamics, Female Pelvic Medicine & Urogenital Reconstruction (SUFU)
Mission is to optimize the care of women, men, and children with lower urinary tract dysfunction and/or pelvic floor disorders through education, research and involvement in health care policy.
- SUFU Annual Meeting and Winter Meetings
The International Society for the Study of Vulvovaginal Disease (ISSVD)
Its goal is to promote international communication among gynecologists, pathologists, dermatologists, and related disciplines, to establish international agreement on terminology and definitions of vulvovaginal diseases and to promote clinical investigation, basic research, and dissemination of knowledge in this field.
- World Congress of the ISSVD

International Association for the Study of Pain (IASP)
The IASP works to support research, education, clinical treatment, and better patient outcomes for all pain conditions with the goal of improving pain relief worldwide.
- World Congress on Pain
- Abdominal and Pelvic Pain World Congress, organized by IASP Abdominal & Pelvic Pain special interest group.
- Terminology & Classification
- Journal: Pain

European Pain Federation (EFIC)
A multidisciplinary professional organisation in the field of pain research and medicine.
- Annual Congress
- Journal: European Journal of Pain

International Pelvic Pain Society (IPPS)
Its goal is to promote education about interdisciplinary approaches to the evaluation and treatment of health conditions associated with chronic pelvic pain, support individuals living with chronic pelvic pain and raise public awareness through education, outreach and engagement and improve the lives of patients worldwide.
- Annual Scientific Meeting on Pelvic Pain

Convergences PP – Convergences in Pelvi-Perineal Pain
- Annual Scientific Meeting

European League Against Rheumatism (EULAR)
A European organization which represents people with rheumatic diseases, health professionals and scientific societies of rheumatology of all the European nations.
- EULAR: Annual European Congress of Rheumatology

NURSING SOCIETIES
International Council of Nurses (ICN)
Society of Urologic Nurses and Associates (SUNA)
European Association of Urology Nurses (EAUN)
PHYSIOTHERAPY

**World Confederation for Physical Therapy**

- with sub-group *International Organization of Physical Therapists in Pelvic and Women’s Health (IOPTPWH)*

HEALTH AUTHORITIES

**World Health Organization (WHO)**

**WHO ICD-11**

The International Classification of Diseases (*ICD-11*) is a global categorization system for physical and mental illnesses published by the World Health Organization.

**National Institutes of Health/National Institute of Diabetes, and Digestive and Kidney Diseases (NIH/NIDDK)**

- *Interstitial Cystitis (Painful Bladder Syndrome)*
- *Multidisciplinary Approach to the Study of Pelvic Pain (MAPP)*

**US Food & Drug Administration (FDA)**

**European Medicines Agency (EMA)**

PATIENT UMBRELLA ORGANISATIONS (GENERAL)

**European Patients' Academy (EUPATI)**

A pan-European project implemented as a public-private partnership by a collaborative multi-stakeholder consortium from the pharmaceutical industry, academia, not-for-profit, and patient organisations. Focuses on education and training to increase the capacity and capability of patients to understand and contribute to medicines research and development and also improve the availability of objective, reliable, patient-friendly information for the public.

**European Patients Forum (EPF)**

EPF is an umbrella organisation that works with patients’ groups in public health and health advocacy across Europe. Its members represent specific chronic disease groups at EU level or are national coalitions of patients.

CLINICAL TRIALS

Clinical Trials Portals: search the licensed registries of clinical trials

**International Clinical Trials Registry Platform (ICTRP)**

**ClinicalTrials.Gov**

**International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)**
Fowler’s Syndrome
First described in 1985, it is a cause of urinary retention (inability to pass water normally) in young women. Urinary retention in young women is not common but can be quite debilitating. The abnormality lies in the urethral sphincter (the muscle that keeps you continent). The problem is caused by the sphincter’s failure to relax to allow urine to be passed normally. There is no neurological disorder associated with the condition. Up to half the women have associated polycystic ovaries.