

**INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME,
HUNNER LESION DISEASE, CHRONIC PELVIC PAIN
AND ASSOCIATED DISORDERS**

Global Patient Organizations, Support Groups and Websites

If your organization is not listed here or if you wish to change your details,
please contact info@painful-bladder.org

Global IC/BPS Patient Advocate Network

Network of global IC/BPS patient advocates promoting
and representing the interests of IC/BPS patients

Contact: Mathilde Scholtes

Email: mjmjscholtes@icloud.com

Email: info@icbpsadvocates.org

Website:

Language: English

AUSTRIA

Interstitielle Zystitis (IC) Österreich

Support Group for IC/BPS patients

Chair: Christa Rammerstorfer

Website: <https://www.ica-austria.at>

Email: rammerstorfer@chronischkrank.at

Language: German

CANADA

The Happy Pelvis

Guidance and support for patients for managing chronic pelvic pain,
including IC/BPS, endometriosis and pelvic floor dysfunction.

Chair: Michelle Withers

Website: <https://thehappypelvis.ca/>

E-mail: michelle@thehappypelvis.ca

Language: English

Pelvichealthsupport.org - phs

Pelvic Health education. Real answers. Expert Guidance.

Whole-Person Support. USA and Canada

Contact: Marnie Glavin

Website: <https://pelvichealthsupport.org/>

Email: info@pelvichealthsupport.ca

Language: English

DENMARK

IC Foreningen

Patient support group for IC/BPS.

Chair: Signe Heister

Website: <http://www.icforeningen.dk/>

Email: signe.heister@icforeningen.dk

Language: Danish

FRANCE

Association Française de la Cystite Interstitielle (AFCI)

Patient support group for IC/BPS.

Chair: Morgane Doyen

Website: <https://asso-afci.org/>

Email: ci_france@hotmail.com

Language: French

Association d'Information sur la Névralgie Pudendale et les Douleurs Pelvi-Périnéales (AINP)

AINP supports people with pudendal neuralgia and pelvic-perineal pain.

President: Nicole Briand

Website: <https://www.association-ainp.com/>

Email: ainp44@gmail.com

Language: French

GERMANY

Verein für Blasenschmerzsyndrom & IC Deutschland e.V.

Patient Association for Bladder Pain Syndrome & Interstitial Cystitis.

With list of self-help support groups. Covers Germany, Switzerland and Austria

Chair: Yvonne Skarlatoudis

Website: <https://www.ic-deutschland-verein.de/>

Email: info-ic@gmx.de

Language: German

IC-Netforum.de

Online self-help platform for Interstitial Cystitis and Bacterial Urinary Tract Infections.

Contact: Sybille Adamsen

Website: <https://www.ic-netforum.de>, www.interstitielle-zystitis.de

Email: ic-netforum@t-online.de

Language: German

Deutsche Kontinenz Gesellschaft e. V.

German Continence Society

Website: <https://www.kontinenz-gesellschaft.de/>

Link to expert search for IC centres in Germany:

[IC-Zentren - Deutsche Kontinenz Gesellschaft](http://IC-Zentren-Deutsche-Kontinenz-Gesellschaft)

Language: German

INDIA

Interstitial Cystitis India (ICI)

Support and advocacy platform for people living with Interstitial Cystitis/Bladder Pain Syndrome

Chair: Balaka Basu

Website: interstitialcystitisinindia.org (<https://www.patientsengage.com/personal-voices/interstitial-cystitis-gave-me-reason-love-treasure-life>)

Email: icindiaorg@gmail.com

Languages: English, Hindi

Sjögren's India

Contact: Kirtida Oza

Website: <https://www.sjogrensindia.org/>

Email: kirtidaoya@gmail.com

ISRAEL

Israeli Association of Bladder Syndromes

Association for the Promotion of Awareness of Bladder Diseases and Syndromes

Chair: Yafit Shoval

Website: www.Shalpuchit.co.il

Email: Yafit2530@gmail.com

Language: Hebrew

ITALY

Associazione Italiana Cistite Interstiziale (AICI)

Patient support group for IC/BPS

President: Loredana Nasta

Website: <http://www.aicionlus.org/>

Email: info@aici-onlus.it

Email: segreteria@aici-onlus.it President: Loredana Nasta

Language: Italian

JAPAN

Information website for IC/BPS patients:

Website: <http://www.pikara.ne.jp/ichi5-ichie/>

NETHERLANDS

Interstitiële Cystitis Patiententenvereniging (ICP)

Patient support group for IC/BPS

Chair: Carla Velkamp

Secretariaat: Karin Hesselink (Postbus 91, 4000 AB Tiel)

Email: info@icpatienten.nl

Website: <https://icpatienten.nl/>

Language: Dutch

Nationale Vereniging Sjögrenpatiënten

Email: info@nvsp.nl

Website: <https://www.nvsp.nl/>

Facebook: www.facebook.com/www.nvsp.nl

Stichting Bekkenbodem4All

Support for patients with pelvic floor disorders

Website: <https://bekkenbodem4all.nl/>

Email: [info@bekkenbodem4all](mailto:info@bekkenbodem4all.nl)

NEW ZEALAND

New Zealand Painful Bladder Support Group NZPBSG

Painful bladder patient support group

Chairman: Dot Milne

Website: <https://www.nzpbsg.org/>

Email: dot@nzpbsg.org;

Language: English

ROMANIA

Cistita.ro

Website dedicated to communicating with people suffering from acute, chronic cystitis, painful bladder, chronic prostatitis, chronic pelvic pain of bladder origin in women or prostate in men, overactive bladder, frequent urination, urination at night.

Contact and organizer: Dr Andrei Manu Marin

Website: <https://www.cistita.ro>

Language: Romanian

Asociatia de Cistita Interstitiala si Reabilitare Perineala

<https://www.facebook.com/perineu/>

SOUTH AFRICA

Mpho ya Lesedi (MLO)

Support groups for IC/BPS

Chair: Maureen Morapeli

Facebook: <https://www.facebook.com/YaLesedi/>

Email: info@mylesedi.co.za

Language: English

SPAIN

Asociacion Catalana de Afectados de Cistitis Intersticial/Síndrome del Dolor (ACACI)

[Patient association for Spanish patients suffering from IC/BPS](#)

President: Esther Sierra

Website: <https://www.acaci.es/>

Email: info@acaci.es

Language: Spanish

Associació de Dolor Pèlvic Perineal Crònic (ADOPEC)

Chronic Pelvic Pain Association for Spain

Contact: Noelia Dorado Pizarro

Website: <https://www.dolorpelvico.org/>

Email: info@adopec.org

Language: Spanish

Asociación Española Síndrome de Sjögren

Email: info@aesjogren.org

Website: <https://aesjogren.org/>

UNITED KINGDOM

Bladder Health UK

Support group for patients with different bladder conditions including IC/BPS

Contact: Millie Baker

Website: <https://bladderhealthuk.org/>

Email: info@bladderhealthuk.org

Language: English

Pelvic Pain Support Network

Provides support, information and advocacy for those with Pelvic Pain

Contact: Judy Birch

Website: <https://www.pelvicpain.org.uk/>

Email: info@pelvicpain.org.uk

Language: English

British Sjögren's Syndrome Association

Website: <https://sjogrensuk.org/>

Email: office@bssa.uk.net

UNITED STATES

Interstitial Cystitis Association - ICA

National patient organization for Interstitial Cystitis/Bladder Pain Syndrome

Executive Director: Laura Santurri

Website: <https://www.ichelp.org/>

Email: ICAmail@ichelp.org

Language: English

Interstitial Cystitis Network – ICN

Provides online IC activities, downloads, videos, courses, books and apps

Contact: Jill Osborne

Website: www.icnetwork.org

Email: icnetwork@mac.com

Language: English

INTERNATIONAL ORGANIZATIONS

International Painful Bladder Foundation – IPBF

The IPBF promotes the interests of IC/BPS patients around the globe, and knowledge and awareness of IC/BPS and associated disorders

Chair: Jane Meijlink

Website: <https://www.painful-bladder.org/>

Email: info@painful-bladder.org

Language: English

EURORDIS - European Organization for Rare Diseases

Empowers, partners, and advocates for people living with a rare disease in Europe

Website: <https://www.eurordis.org/>

Orphanet

Database on rare diseases and orphan drugs

Website: <https://www.orpha.net/>

International Sjogren's Network

Website: <https://sjogrens.org/living-with-sjogrens/support-groups-networks/international-sjogrens-network>

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