

**INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME,
HYPERSENSITIVE BLADDER, CHRONIC PELVIC PAIN
AND ASSOCIATED DISORDERS**

Global Patient Organizations, Support Groups and Country Contacts

click on the name to jump to the site (if available)

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

AUSTRALIA

Continence Foundation of Australia

Suite 1, 407 Canterbury Road,
Surrey Hills, VIC 3127, Australia
Telephone: 03 8692 8400
Fax: 03 9380 1233
info@continence.org.au

AUSTRIA

ICA Austria

Contact: Christa Rammerstorfer
Tel: +43 (0) 676/6760 023
Email: rammerstorfer@chronischkrank.at;

Chronischkrank Österreich

kontakt@chronischkrank.at

BRAZIL

Interstitial Cystitis Patient Support North East Brazil

Contact: Ariel Scafuri MD
Rua Republica do Libano, 1513 - Varjota, Fortaleza,
Ceara - CEP 60175-222, Brazil
Tel +5585999271133
Email - urologia@gmail.com
Skype ascafuri
Facebook - www.facebook.com/urologia
<https://www.facebook.com/clinicaarielscafuri/>

Sao Paulo region

Contact: Fernando Almeida, MD, PhD
Female Urology & Voiding Dysfunction
Federal University of Sao Paulo UNIFESP-EPM
Tel: 55-11-5576 4086
website: www.drfernandoalmeida.com.br

CANADA

PELVIC HEALTH SUPPORT (PHS) CANADA

PHS Canada is a newly launched digital resource support group that aims to raise awareness, educate and support those living with pelvic health conditions including interstitial cystitis/bladder pain syndrome.

<https://www.pelvichealthsupport.ca/>

Kitchener-Waterloo IC Support Group – ONTARIO

Contact: kwicsmail@gmail.com

Calgary Interstitial Cystitis (IC) Group

Vancouver IC Group

CZECH REPUBLIC

Contact: Libor Zamecnik, MD

Urologická Klinika

VFN a 1. LF UK, Ke Karlovu 6 128 08 Praha 2

Czech Republic

Email: libor.zamecnik@lf1.cuni.cz

DENMARK

IC Foreningen

Maria Lukowski

maria.lukowski@gmail.com;

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

FRANCE

Association Française de la Cystite Interstitielle

Chairman: Françoise Watel, francoise.watel@numericable.fr;

barbara.e.jankowski@gmail.com;

Email: Info.asso.afci@gmail.com; ci_france@hotmail.com;

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

GERMANY

<https://www.ic-netforum.de>

Sybille Adamsen

Tel.: 022054479

Email: ic-netforum@t-online.de

GREECE

Michael Samarinas MD PhD
00306946006798
Urology Consultant
Head of the Urodynamics Unit
Head of the Neuropathic Pelvic Pain Clinic
General Hospital of Larissa, Greece
HUA Patient Office, Steering Committee Member
<https://www.huanet.gr/γραφειο-ασθενων/>

Center for Urologic and Pelvic Pain

Contact: Konstantinos Kalyvas, MD
Thessaloniki Makedonia, Greece
Tel/Fax 0030 2310-32 40 20
kalyvas@cpc.gr

HUNGARY

Hungarian IC/BPS Patient Association

President: Zita Gódor Hazenauer
Email: hasenauerzita@gmail.com

INDIA

Interstitial Cystitis India (ICI)

Contact: Balaka Basu
icindiaorg@gmail.com

Interstitial Cystitis Center Ahmedabad

Contact: Dr Nagendra Mishra, urologist
Tel: 079- 27497083
nagendraad1@yahoo.com
<http://www.interstitialcystitisbladderpaincenter.com/>

Sjögren's India

Contact: Kirtida Oza
Email: kirtidaoza@gmail.com

ISRAEL

The Israeli Association for Bladder Syndromes

Chair: Yafit Avidan Shoval
Email: yafit2530@gmail.com
Email: shalpuchit2013@gmail.com
<https://www.facebook.com/399672920179408> העמותה למחלות ותסמונות של-שלפוחית השתן-
<http://shalpuchit.co.il>

ITALY

Associazione Italiana Cistite Interstiziale (AICI)

President: Loredana Nasta

Via Nomentana 133, 00162 Rome, Italy

Tel: 06-4402674

Email: info@aici-onlus.it

Email: segreteria@aici-onlus.it

UNIAMO

Rare Diseases Italy

JAPAN

CUN (Comfortable Urology Network)

info@hainyo-net.org

NETHERLANDS

Interstitiële Cystitis Patiententenvereniging (ICP)

Chair: Hilde Andriesse

Simon van Haarlemstraat 2, 4003 XG Tiel

Postal address: Postbus 91, 4000 AB TIEL

Tel: (030) – 656 96 32

Email: info@icpatienten.nl

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

Nationale Vereniging Sjögrenpatiënten

Postbus 6

3600 AA MAARSEN

Email: info@nvsp.nl

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

Stichting Bekkenbodem4All

Postbus 91

4000 AB Tiel

Tel: 030 656 96 30

info@bekkenbodem4all

NEW ZEALAND

New Zealand Painful Bladder Support Group NZPBSG

Chairman: Dot Milne

P.O. Box 41168, Christchurch 8247, New Zealand

Email: dot@nzpbsg.org;

NORWAY

Norsk Forening for Pasienter med Urologiske Sykdommer og Inkontinens (NOFUS)
post@nofus.no

POLAND

Contact: Piotr Radziszewski MD
Department of Urology Warsaw School of Medicine
pradziszewski@wum.edu.pl

NTM – Normalnie Życ (To Live a Normal Life)

Polish Continence Society
ul. Hajoty 49, 01-821 Warszawa
Director: Tomasz Michałek:
Tel. +48 22 279 49 01
Email: tomasz.michalek@ntm.pl
Email: ntm@ntm.pl

Polish IC/PBS patient website

PORTUGAL

Contact: Ana Charrua Cordeiro PhD,
Porto University,
anacharr@gmail.com;

Contact: Paulo Dinis Oliveira MD
Dept of Urology Hospital S. João
4200 Porto, Portugal
paulodinisoliveira@gmail.com

ROMANIA

Cistita.Ro

Contact: Andrei Manu-Marin, MD
andri_66@yahoo.com

Asociatia de Cistita Interstitiala si Reabilitare Perineala
<https://www.facebook.com/perineu/>

SOUTH AFRICA

Mpho ya Lesedi (MLO)

Chair: Maureen Morapeli
Info@mylesedi.co.za
<https://www.facebook.com/YaLesedi/>

SPAIN

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

President: Asunción Caravaca Marín

Email: info@acaci.es

Cistitis Intersticial ABATYCI

<https://www.facebook.com/abatyci.cistitisintersticial>

Associació de Dolor Pèlvic Perineal Crònic (ADOPEC)

Contact: Angels Jubert

jubert.angels@gmail.com

Asociación Española Síndrome de Sjögren

Email: info@aesjogren.org, direccion@aesjogren.org

SWEDEN

Sinoba -Swedish organization for Incontinence and Bladder Problems

Email: info@sinoba.se

TAIWAN

Taiwan Interstitial Cystitis Association (TICA)

President: Yu-Chen Lan (藍玉貞)

Email: ic4290@gmail.com

UNITED KINGDOM

Bladder Health UK

Kings Court

17 School Road

Birmingham B28 8JG

Tel: +44-(0)121-7020820

Email: info@bladderhealthuk.org

Bladder and Bowel Community

Forward House

17 High Street

Henley-in-Arden B95 5AA

General Enquiries: 01926 357220

Email: help@bladderandbowel.org

Pelvic Pain Support Network

Contact: Judy Birch

PO Box 6559, Poole, Dorset BH12 9DP, United Kingdom

Email: info@pelvicpain.org.uk

British Sjögren's Syndrome Association

Tel: 0121 478 0222.

Email: office@bssa.uk.net

UNITED STATES

[Interstitial Cystitis Association ICA](#)

7918 Jones Branch Drive, Suite 300
McLean, VA 22102
Email: icamail@ichelp.org

[AARDA](#)

American Autoimmune Related Diseases Association

[American Chronic Pain Association \(ACPA\)](#)

CEO: Penney Cowan
PO Box 850, Rocklin, CA 95677
Phone: 800.533.3231
Email: ACPA@theacpa.org

[National Association for Continence \(NAFC\)](#)

[National Vulvodynia Association](#)

[NORD](#)

National Organization for Rare Disorders

[Interstitial Cystitis Network ICN](#)

Jill Osborne
Email: icnetwork@mac.com

[Simon Foundation for Continence](#)

[Sjögren's Foundation](#)

INTERNATIONAL ORGANIZATIONS

[International Painful Bladder Foundation IPBF](#)

Info@painful-bladder.org

[International Sjogren's Network](#)

[EURORDIS](#)

European Organization for Rare Diseases

[Orphanet](#)

Database on rare diseases and orphan drugs

[International Alliance of Patients' Organizations IAPO](#)

CAN Mezzanine, 49-51 East Road London, N1 6AH, United Kingdom
info@iapo.org.uk

[World Patients Alliance](#)

info@worldpatientsalliance.org

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