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
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Email - urologia@gmail.com
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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

Kitchener-Waterloo IC Support Group – ONTARIO
Contact: kwicsmail@gmail.com

Calgary Interstitial Cystitis (IC) Group
Vancouver IC Group

CZECH REPUBLIC

Contact: Libor Zamecnik, MD
Urologicka Klinika
VFN a 1. LF UK, Ke Karlovu 6 128 08 Praha 2
Czech Republic
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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

Verein für Blasenschmerzsyndrom & IC Deutschland e.V.
Email: info-ic@gmx.de
www.interstitielle-zystitis.de

https://www.ic-netforum.de
Sybille Adamsen
Tel.: 022054479
Email: ic-netforum@t-online.de

Deutsche Kontinenz Gesellschaft e. V. | German Continence Society
Friedrichstraße 15
60323 Frankfurt am Main
Tel.: +49 (0) 69-795 88 395

Fax: +49 (0) 69-795 88 383
https://www.kontinenz-gesellschaft.de/
Link to expert search for IC centres in Germany:
IC-Zentren - Deutsche Kontinenz Gesellschaft

GREECE

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HUA Patient Office, Steering Committee Member
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Center for Urologic and Pelvic Pain
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Thessaloniki Makedonia, Greece
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HUNGARY

Hungarian IC/BPS Patient Association
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INDIA

Interstitial Cystitis India (ICI)
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icindiaorg@gmail.com

Interstitial Cystitis Bladder Pain Centre India
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Sjögren's India
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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
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Tel: (030) – 656 96 32
Email:info@icpatienten.nl
https://www.facebook.com/ICPPatientenvereniging/

Nationale Vereniging Sjögrenpatiënten
Postbus 6
3600 AA MAARSSEN
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
65 St. Andrews Hill Road, Christchurch 8081, 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 Żyć (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 Crònico (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 Continence Society
Website: www.tcs.org.tw/
Email: thaiurogyn@gmail.com
Facebook: www.facebook.com/thaiURGS/

UNITED KINDGOM

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

PELVIC HEALTH SUPPORT (PHS)

PHS is a digital resource support group for North America that aims to raise awareness, educate and support those living with pelvic health conditions including interstitial cystitis/bladder pain syndrome.
https://pelvichealthsupport.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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