



INTERSTITIAL CYSTITIS ASSOCIATION

Patients, Researchers, Clinicians . . . Putting the Pieces Together

Inter . . . What?

Interstitial (IN-tur-STISH-ul) cystitis (sis-TI-tis)



- Chronic, painful condition, also known as “IC” and painful bladder syndrome (PBS)
- Pelvic pain, pressure, or discomfort related to the bladder typically associated with a persistent urge to void or urinary frequency, in the absence of infection or other pathology
- Unknown cause
- No cure, but treatment options to relieve symptoms



As Common as Type 1 Diabetes

- More than 1.2 million people
 - All ages, genders, races and ethnicities
 - More common in women
- Impacts quality of life
 - Bathroom breaks in severe cases 60 times per day
 - Pain like shards of glass being ground into the bladder
 - Discomfort and pain with intercourse
 - Depression associated with coping with a debilitating illness
- One of the most costly urologic diseases
 - Annual cost of caring for people with IC: \$66 million
 - Average patient cost: double the norm—\$7,100 (versus \$3,000)

Putting the Pieces Together

The ICA gives a voice and hope to people who suffer from interstitial cystitis by:

- Providing comprehensive and up-to-date information on IC
- Offering support for people with IC, their families, and friends
- Educating the medical community and public about IC
- Advocating for IC patients, healthcare providers, and researchers
- Promoting and funding research to find effective treatments and a cure





Working with the Experts

ICA Medical Advisory Board

Board Co-Chairs

Alan Wein, MD

University of Pennsylvania Health System

Philip M. Hanno, MD

University of Pennsylvania Health System

Members

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Center for Medical Pain Management

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University of Alabama at Birmingham

Kristene E. Whitmore, MD

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Special Consultant

Monica Liebert, PhD

University of Michigan

Liaisons to NIDDK

Leroy M. Nyberg, MD, PhD

NIDDK, National Institutes of Health (NIH)

Chris Mullins, PhD

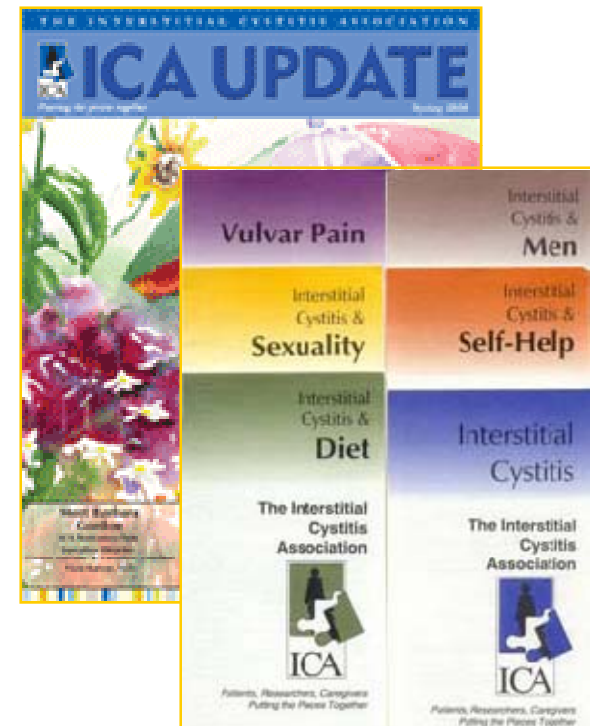
NIDDK, NIH

THE INTERSTITIAL CYSTITIS ASSOCIATION

Putting the pieces together

Authoritative Information

- ICA Update (quarterly magazine)
- www.ichelp.org (24 / 7 information)
- Café ICA (on-line news digest)
- Health information materials
 - Overview of IC
 - Treatment options
 - Quality of life issues
 - Related conditions
- Regional forums
- Scientific meetings

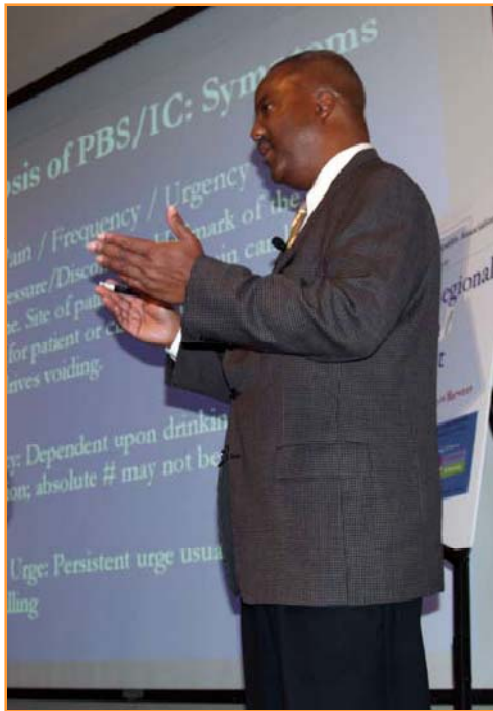


Telephone and Online Support



- 800-HELP ICA
 - Answer more than 600 phone calls each month
- Question Corner
 - Respond to over 125 emails each month
- Patient support advocates
 - National network of volunteers
- Healthcare provider registries
 - US and international listings of healthcare providers who treat IC
- Social Security disability support
 - Help patients navigate the benefits process

Public and Medical Education



- Promoting public awareness
 - ICA Champions—physicians and patients available for local interviews
 - New York Times, Washington Post AP newswire
 - SELF, Family Circle, Good Housekeeping
 - Urology Health Extra
- Offering targeted medical education
 - Healthcare Provider Education Kits
 - Physician Perspectives (cheat sheet)
 - CME seminars
 - Network and exhibit at professional meetings
 - Educational materials for allied health continuing education seminars

Disability and Research Advocacy

- Working with the Social Security Administration
 - Obtained Social Security disability ruling
- Advocating for federal research funding
 - Facilitated more than \$100 million in federal funds—thus far
- Forming coalitions with patient advocacy groups and other stakeholders
 - Overlapping conditions
 - Chronic pain
 - Pelvic pain
 - Women's health



Research Funding and Promotion

- ICA Pilot Research Program
 - Recent research includes the role of mast cells and an epidemiologic study of patient trends
- Fishbein Family Foundation IC Research Foundation
 - Current focus includes developing a test for IC and understanding more about antiproliferative factor (APF)



Making a Difference

Tangible Progress

- Moving IC from being thought of as a hysterical women's disease to a real physical problem
- Putting IC in the vocabulary of the urologists and other healthcare providers
- Getting dedicated IC research in the budget of the NIH
- Partnering with CDC to raise awareness
- Giving a voice and hope to millions of people



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