



Conquering IC.
Changing Lives.

Interstitial Cystitis Association

INTERSTITIAL CYSTITIS ASSOCIATION

Legislative Agenda 117th Congress 2nd Session

The Interstitial Cystitis Association (ICA) provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC. 88% of every dollar received by ICA goes into direct services, benefiting IC patients and working towards fulfilling the organization's mission.

Interstitial cystitis is a bladder condition that consists of multiple symptoms. IC patients have recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region, and urinary frequency (needing to go often) and urgency (feeling a strong need to go). IC may also be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain.

Patient Perspective

My name is Amy Macnow and I was diagnosed with Interstitial Cystitis about three years ago. A chronic bladder disease with no cure. The first time in my life I've been sick with anything serious.

IC is a tough disease to diagnose, so it took some time. That is one of the most challenging things to deal with, finding a Dr. that specializes in IC that can help diagnose and treat. I can't stress enough how important finding the right Dr. is. IC patients need a Dr. who understands and is willing to go along with them on this long, frustrating, painful and confusing road. I have found strength through having this that I never knew I had, strength to keep going when all treatments so far have failed me.

There are a small number of treatments available for managing IC symptoms, but they only work on a small percentage of patients. I have tried those treatments and some drugs that "might" help. I manage my diet, take lots of supplements and have to see all kinds of Doctors now. I have six! That includes holistic medicine doctors, physical therapists, and acupuncturist. That's along with my regular MD, Urologist and two different gynecologists. This is what my life has become. The life of an IC patient.

I deal with one or more symptoms of IC EVERY SINGLE DAY. Some days definitely better than others, but every single day. It affects my life in so many ways. Work, social, travel and my intimate relationships. I never know how I'm going to feel from one day to the next. Anxiety and fear included.

I must say I am a bit hopeful though. Hopeful that with more awareness raised we will start seeing more treatments, more trials. More research and funding so one day there will be a cure. That is what I hope for. I can learn how to live with IC. I have learned to be strong, but I want to feel better. I want to be healthy again. I am one of millions who feel this way.



FY 2023 Funding Priorities

- **Please provide \$1,500,000 for the IC Education and Awareness Program at the Centers for Disease Control and Prevention's (CDC).** This program promotes public awareness of IC through education for health care providers and the public. As a diagnosis of exclusion, physicians must be aware of IC for patients to receive timely and accurate diagnoses and this program maintains a significant focus on information sharing among stakeholders, with the aim to increase awareness, diagnosis, and proper treatment.
- **Please provide the National Institutes of Health (NIH) with at least \$49 billion in FY 2023.** The cause of IC is unknown, there are no definitive diagnostic tools available to clinicians, and there is no cure for IC. The National Institute of Diabetes, and Digestive, and Kidney Diseases (NIDDK) leads the NIH research portfolio with groundbreaking studies like the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network which takes a whole-body approach to studying IC as well as epidemiology research
- **Please include "interstitial cystitis" as conditions eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2023.** IC is becoming increasingly prevalent among veterans and is associated with post-traumatic stress disorder. Congress has historically included IC in the list of eligible conditions for research under this program and IC researchers compete successfully each year.

2022 Policy Priorities

Maintain access to chronic pain care medication and protect the patient/doctor relationship with regards to prescriptions. Chronic pain patients depend on important medications to cope with their pain.

The vast majority of IC patients often suffer major and multiple quality of life issues due to this condition. Many IC patients are unable to work full time because pain affects their mobility, sleep, cognition, and mood. These are people that simply want to lead productive lives, and need pain medication to do so. Due to the fact that IC is categorized as a non-cancer pain condition, IC patients already have a difficult time obtaining pain meds. IC doctors do not have time nor the inclination to effectively prescribe or monitor the distribution of the opioid class of medication. They often refer their patients to Pain Management Specialists, many who have never heard of IC, who often refuse to treat them. In addition, antidepressants and benzodiazepines are often used to treat both mood and sleeping disorders for IC patients.

ICA fully supports educating providers with the full spectrum of pain management regarding effective treatment for all patients. We understand the current epidemic with prescription misuse, abuse and overdoses, however we represent patients who rely on responsible use to live a normal life. Pain management is wide reaching and does not only include prescribing health providers but also physical therapists who assist patients working on their pelvic floor to alleviate and manage pain. These practices can lead to a patient moving away from prescription usage while maintaining the same quality and results of care.