

INTERSTITIAL CYSTITIS ASSOCIATION Legislative Agenda 117th Congress 1st 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 Claudia King, and I live with IC. I was diagnosed with IC in 2005, just a month before my wedding. But my journey started long before. I had constant bladder infections, painful urination, and lower back pain and pressure that felt like fifty-pound hooks hanging from my hips. I also didn't go to the bathroom very often, and when I did, it was a struggle. I had to push so hard just to pee. But, I thought all these things were normal, because it was what I had known since high school.



My path to a diagnosis was a humiliating one.

I remember vividly going back to my primary doctor after three days of antibiotics for a urinary tract infection. I was still in a lot of pain and experiencing urgency and frequency, so I figured I just needed another round of antibiotics. The doctor came in and very matter-of-factly said, "You don't have an infection anymore. You must have an STD. We'll run tests for them to see which one it is." I was horrified, embarrassed, and in shock. I knew I didn't have an STD, but this doctor wasn't giving me any choice. In my mind, he was declaring me a person unworthy of anything other than a sexually-transmitted disease.

Tests were run, and they were all negative. For me, the damage was done. The humiliation and anger I felt couldn't be erased. There were no apologies and no other help from the doctor, other than to say, "I guess your endometriosis is back. You should see your gynecologist." Truthfully, in that moment, I was happy he was giving up on me and sending me back to the most compassionate doctor I knew. I called my gynecologist, and when he had me run through my symptoms, he said, "You have interstitial cystitis. Come see me to confirm the diagnosis." The next day, a potassium sensitivity test (please note that this procedure is no longer used) was performed, and it only took the tiniest amount of potassium injected into my bladder for the pain to set in and for the doctor to declare officially that I was now an IC patient.

My journey had only just begun.

I had no idea how IC would change my life. I was lucky enough to find one of the premier IC doctors, Dr. Robert Evans, nearby in Greensboro, NC. His kind, compassionate, cutting-edge care took me from a person who couldn't work anymore to someone who felt more-or-less human on most days. But, I couldn't have survived, especially in those early times immediately following my diagnosis, without the Interstitial Cystitis Association (ICA). The ICA was the first organization I came across that provided support and information and let me know that I was not alone.

FY 2022 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 general public. As a diagnosis of exclusion, physicians must be aware of IC in order 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 \$46.1 billion in FY 2022.** 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 continue to include “interstitial cystitis” as conditions eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2021.** 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.

2021 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.

ISSUE BRIEF

“Please provide \$1,500,000 for the IC Education and Awareness Program at the Centers for Disease Control and Prevention’s (CDC)”

Background

The CDC IC Education and Awareness Program is the only federal program dedicated to improving public and provider awareness of this devastating disease, reducing the time to diagnosis for patients, and disseminating information on pain management and IC treatment options. ICA has been working with CDC to increase the amount of dedicated funding for education and awareness as part of the IC Program. The IC Education and Awareness program has utilized opportunities with charitable organizations to leverage funds and maximize public outreach. Such outreach includes public service announcements in major markets and the internet, as well as a billboard campaign along major highways across the country. The IC program has also made information on IC available to patients and the public through videos, booklets, publications, presentations, educational kits, websites, self-management tools, webinars, blogs, and social media communities such as Facebook, YouTube, and Twitter. For healthcare providers, this program has included the development of a continuing medical education module, targeted mailings, and exhibits at national medical conferences.

The Issue

The CDC IC Education and Awareness Program provides patient support that empowers patients to self-advocate for their care. For this reason, it is especially critical for the IC program to provide patients with information about what they can do to manage this painful condition and lead a normal life. ICA urges Congress to provide \$1,500,000 for the IC Education and Awareness Program with recommended increased education and awareness activities in FY22.

ISSUE BRIEF

“Increase Funding for the National Institutes of Health”

(This will be of particular interest to members of the House and Senate Appropriations Committees)

Background

The National Institutes of Health (NIH) is the world’s foremost biomedical research enterprise. Much of the research activities supported by NIH do not take place in Washington, DC, but at academic medical centers across the country. Medical researchers compete for funding for their projects by submitting grants and going through a peer-review process that ensures the highest-quality grants receive funding.

Presently, NIH supports interstitial cystitis research through the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institute of Neurological Disorders and Stroke (NINDS), and other relevant institutes and centers.

The Issue

Each year, Congress balances medical research against other federal priorities and decides how much funding will be provided to NIH through the appropriations process. In FY 2022, we ask that Congress provide NIH with a meaningful funding increase of \$3 billion to bring the agency’s funding to \$46.1 billion.

ISSUE BRIEF

“Continue to Include Interstitial Cystitis in Defense Research Activities”

(This will be of particular interest to members of the House and Senate Appropriations Committees)

Background

In addition to research funded through NIH, the federal government supports research through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP). Unlike NIH, which funds meritorious grants on any condition, the PRMRP only supports research into conditions that are on a list that deems them eligible for study. Each year, Congress decides which conditions are placed on the eligible conditions list and the list itself appears through the appropriations process. Interstitial Cystitis has been included on the PRMRP eligible conditions list in recent years, which has led to over \$19 million in research funding.

The Issue

The eligible conditions list changes each year, and being included one year is no guarantee of continued participation. Legislators decide what conditions to place on the eligible conditions list based on feedback from constituents. 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. For FY 2022 we are asking legislators to continue to support the inclusion of “interstitial cystitis” as a condition eligible for study through the PRMRP.

ISSUE BRIEF

“Maintain access to chronic pain care medication and protect the patient/doctor relationship with regards to prescriptions”

Background

The opioid epidemic has ravaged communities across the country. While Congress debates solutions to this crisis, they must consider and protect the needs of chronic pain patient communities who depend on appropriate medications.

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Talking Points

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.