



Conquering IC.
Changing Lives.

Interstitial Cystitis Association

2022

Annual Report

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Throughout 2022, the Interstitial Cystitis Association continued its mission of advocacy, research, and education to improve the lives of the more than 12 million Americans suffering from IC/BPS.

• • • FROM THE EXECUTIVE DIRECTOR • • •

As it approaches nearly four decades of service, ICA remains the voice of the more than 12 million people in the interstitial cystitis/bladder pain syndrome (IC/BPS) community. In 2022, the association continued to deliver on its promise to advocate, educate, and support research to improve the lives of those with IC/BPS and ultimately find a cure.

Throughout the year, ICA provided educational offerings featuring healthcare providers, researchers, and IC/BPS patients. ICA's annual *Step Up for IC/BPS—ICA Awareness Walk*, as well as a self-guided Spring into Summer Self-Care Adventure, provided multiple opportunities to learn and educate others. Our newly redesigned website, ichelp.org, continues to emphasize these and other educational offerings, which can be accessed anywhere, anytime.

ICA continues to be the only organization representing the interests of IC/BPS patients on Capitol Hill. Along with our successful virtual Advocacy Days in May, ICA staff and leadership met with Congressional leaders and provided IC/BPS patients with the tools needed to educate their representatives throughout the year.

IC/BPS research took a large step forward with the first revision of the American Urological Association (AUA) clinical treatment guideline since 2014. ICA also highlighted opportunities for IC/BPS patients to participate in clinical trials, including efforts to ensure greater participation in research by historically underrepresented populations.

But it is you, our members, advocates, and supporters, that allow us to fulfill our critical mission of improving the quality of care and the lives of people with IC/BPS. With your help, we will continue to provide opportunities to connect, learn, advocate—and hope—for many years to come.

Thank you for your continued support. We can't do it without you!

With gratitude,

Lee K. Lowery, MPA, CAE
ICA Executive Director

Give Hope, Change Lives

The ICA is the only nonprofit organization dedicated to improving the quality of healthcare and lives of people living with IC/BPS and is a 501(c)(3) organization (EIN 13-3292137). Your support helps ICA provide advocacy, research funding, and education to ensure optimal dignity for people affected by IC/BPS. To learn more, visit ichelp.org/donate.



• • • ADVOCACY • • •

ICA advocates for the needs of the 12 million Americans with interstitial cystitis/bladder pain syndrome, as well as those of the healthcare providers, researchers, and others who work to improve the lives of IC/BPS patients. We also empower people with IC/BPS to advocate for themselves and to ensure we maintain momentum and awareness of the condition and those who suffer from it.

IC ADVOCACY: A YEAR-ROUND EFFORT



ICA Advocacy Days were virtual again in 2022, with ICA board members, staff, and volunteers holding meetings with Congressional offices May 23-25. But advocacy is a year-round

effort, and ICA invited the entire IC/BPS community to participate by emailing and calling their representatives to educate them about IC/BPS and how it impacts their lives. Videos recorded by ICA leaders provided insight on how to communicate with lawmakers and the importance of personal stories. Learn more at ichelp.org/get-involved/advocate/participate-in-advocacy-month/.

ICA Leadership also met with Congressional leaders throughout the year to communicate ICA's legislative priorities and signed on to several letters as part of coalitions representing a broad range of patient advocacy organizations. Among the highlights:

- In March, ICA Chair **Mike Greenwell**, ICA Vice Chair **Laura Santurri**, ICA Executive Director **Lee Lowery**, and ICA's Washington representative met with **Rep. Rosa DeLauro's** (D-CT) office to present ICA's legislative priorities. Congresswoman DeLauro is Chair of both the full Appropriations Committee and the Labor, Health, and Human Services (LHHS) Subcommittee.
- In August, Greenwell, Santurri, Lowery, and ICA's Washington representative met with the offices of six Senate LHHS Subcommittee members ahead of their bill release to push for increased IC funding with the Centers for Disease Control and Prevention (CDC). Meetings occurred with the offices of **Sen. Joe Manchin** (D-WV), **Sen. Tammy Baldwin** (D-WI), **Sen. Marco Rubio** (R-FL), **Sen. Jeanne Shaheen** (D-NH), **Sen. Brian Schatz** (D-HI), and **Sen. Dick Durbin** (D-IL).
- Calling the COVID-19 pandemic "the earthquake that has triggered a tsunami of chronic disease," ICA signed on to a letter to the Healthy Future Task Force's Security Subcommittee, one of seven issue-specific task forces announced by U.S. House of Representatives Republican Leader **Kevin McCarthy** (R-CA). The letter, which was co-signed by nearly three dozen patient advocacy organizations, stressed that the United States has failed to adequately and consistently prioritize funding for the prevention of chronic diseases and conditions and the promotion of health and well-being, and that this failure has made our nation more vulnerable to severe illness and death from infectious disease.
- Joining forces with 33 other patient, provider, healthcare, and research organizations, ICA signed on to letters urging Congress to promptly pass the final Fiscal Year (FY) 2022 appropriations bills with a robust increase for the National Institutes of Health (NIH), including the work of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

ICA's 2022 Legislative Priorities

FY 2023 FUNDING PRIORITIES:

- **Provide \$1,500,000 for the IC Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).** This program promotes public awareness of IC/BPS through education for health care providers and the public. As a diagnosis of exclusion, physicians must be aware of IC/BPS 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.
- **Provide the National Institutes of Health (NIH) with at least \$49 billion in FY 2023.** 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/BPS as well as epidemiology research.
- **Include "interstitial cystitis" as conditions eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2023.** IC/BPS is becoming increasingly prevalent among veterans and is associated with post-traumatic stress disorder. Congress has historically included IC/BPS in the list of eligible conditions for research under this program, and IC/BPS 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/BPS patients often suffer major and multiple quality of life issues due to this condition. Many IC/BPS 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/BPS is categorized as a non-cancer pain condition, IC/BPS patients already have a difficult time obtaining pain meds. IC/BPS doctors do not have time nor the inclination to effectively prescribe or monitor the distribution of the opioid class of medication and often refer their patients to Pain Management Specialists, many of whom have never heard of IC/BPS and often refuse to treat them. In addition, antidepressants and benzodiazepines are often used to treat both mood and sleeping disorders for IC/BPS 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.

ADVOCATE FOR IC/BPS PATIENTS!

Learn how at

ichelp.org/get-involved/advocate/



ICA RESPONDS TO PROPOSED 2022 CDC OPIOID CLINICAL PRACTICE GUIDELINE

ICA submitted comments on the Centers for Disease Control and Prevention (CDC) proposed clinical practice guideline, CDC Clinical Practice Guideline for Prescribing Opioids—United States, 2022, in April, stating that it “fully supports educating providers with the full spectrum of pain management regarding effective treatment for all patients.”

“More research needs to be done for effective non-opioid treatment options before further limiting an already very limited pain management protocol,” the ICA statement says.

The proposed guideline “is not intended to be applied as inflexible standards of care across patient populations by healthcare professionals, health systems, third-party payers, organizations, or governmental jurisdictions,” the CDC’s summary of the proposed guideline states. “The guideline is intended to achieve the following: Improved communication between clinicians and patients about the risks and benefits of pain treatment, including opioid therapy for pain; improved safety and effectiveness for pain treatment, resulting in improved function and quality of life for patients experiencing pain; and a reduction in the risks associated with long-term opioid therapy, including opioid use disorder, overdose, and death.”

• • • RESEARCH • • •

ICA advocates for government funding dedicated to IC/BPS research, and helps keep the research focused on patients by serving on research steering committees and panels.

AUA IC/BPS GUIDELINES REVISED

The American Urological Association (AUA) revised its clinical guidelines on the diagnosis and treatment of interstitial cystitis/bladder pain syndrome (IC/BPS) for the first time since 2014. Released in May 2022, the new guideline emphasizes that treatment must be “individualized and based on the unique characteristics of each patient” and based on “shared decision-making” between healthcare providers and patients, the AUA said in a statement.

To that end, the updated guideline no longer ranks treatments from first-line through sixth-line tiers “in order to emphasize that shared decision-making, individual patient factors, and clinical judgment are the most important factors in treatment choice.” Instead, the guideline urges “concurrent, multi-modal” treatments across multiple categories, taking care to stress that the options listed under each category are not in any recommended order.

ICA has and will continue to share information about the guideline to patients and practitioners alike. “This guideline is meant to provide direction to clinicians and patients on how to recognize, diagnose, and treat IC/BPS. An important component of that clinical framework is discussion of treatments that should and should not be offered. As the relevant science evolves and improves, this guideline will continue to require amendment to remain consistent with the highest standards of clinical care,” said **J. Quentin Clemens, MD**, chair of the AUA guideline amendment panel and director of female pelvic medicine and reconstructive surgery fellowship at the University of Michigan.

ICA, BOSTON CHILDREN’S HOSPITAL, BLACK HEALTH MATTERS COLLABORATE ON IC/BPS RESEARCH STUDY

In the last year the ICA has played a pivotal role in IC/BPS research at Boston Children’s Hospital. From advertising natural history studies to recruitment for genetics analyses, the ICA has been involved in every aspect of the hospital’s Center for Disease Control (CDC) and Columbia University O’Brien Center for Benign Urology grants. More than 1,500 individuals responded to the demographics survey, driven by ICA’s extensive network and effective recruitment. The results of this survey have already led to several papers being prepared.

ICA also is working with Inspire, Boston Children’s Hospital and Black Health Matters (BHM) on diversity and inclusion in IC/BPS research. The collaboration is intended to ensure that all types of individuals are included in research efforts, as underrepresented patient populations continue to be highly underrepresented in research studies. ICA, BHM, Inspire, and Boston Children’s Hospital (BCH) encouraged these groups to participate in the survey.

LIVING WELL WITH IC/BPS: IC HOPE STUDY RESULTS SHARED

In February, ICA Vice Chair **Dr. Laura Santurri** shared during an ICA webinar the results of the IC Hope Study that she conducted with colleagues at the University of Indianapolis. The purpose of the study was ultimately to better understand how people living with IC/BPS are coping with the condition in effective ways.



To watch the ICA webinar, visit youtu.be/1zUlbKBmPB8.

ICA RECRUITS FOR TEXT-BASED CLINICAL TRIAL

ICA helped recruit patients to participate in a research study conducted by the **University of Pennsylvania’s Division of Urogynecology**, which is evaluating a smartphone-based program that teaches patients how to self-manage symptoms.

Short for Educational Remote IC/BPS Aide, ERICA delivers text-based reminders and video modules on evidence-based, holistic self-care strategies and provides support through check-ins that include an option to talk to a clinician.

ICA ENCOURAGES APPLICATIONS TO FDA PATIENT ENGAGEMENT COLLABORATIVE

ICA encouraged IC/BPS patients and those who support them to apply as new members of the **Food and Drug Administration (FDA) Patient Engagement Collaborative (PEC)**. The PEC is a group of patient organizations and individual representatives who discuss ways to enhance patient engagement. The PEC is made up of patients who have personal disease experience, caregivers who have personal experience supporting someone with a health condition, and representatives from patient groups who have direct or indirect disease experience.

• • • EDUCATION • • •

ICA arms patients, healthcare providers, caregivers, researchers, and the general public with objective and up-to-date information about IC/BPS.

VIRTUAL WALK FOR IC/BPS RAISES \$28,000, SPREADS AWARENESS



The ICA 2022 Virtual Fall Fundraiser - Step Up for IC/ BPS Awareness and Educational event that took place online—and everywhere—September 19-24, raised over \$22,000 for greater IC/BPS awareness, better treatments, and an eventual cure for IC/BPS.

For the third year running, participants came together virtually for the annual *Step Up for IC/BPS—ICA Awareness Walk*. Over 180 participants took more than 2.5 million steps during the virtual walk. The **Toth Family** and **SPX Corporation** matched individual donations up to \$5,000 each to triple the impact for the third consecutive year.

Participants received information on the updated American Urological Association guidelines for IC/BPS, sexual health, pelvic floor physical therapy, health insurance, and other video offerings, all while working to raise awareness and funds for better IC/ BPS care everywhere.

Sponsors who helped make the 2022 Fall Fundraising, Awareness and Educational event a success included **Algonot Cysto Protek**, **Desert Harvest**, and **West Coast Mint**. IC/BPS professionals who provided expert educational content included **Dr. Robert Moldwin**, **Dr. Nicole Cozean**, **Tacha Kasper, MA, LMFT**, **Dr. Reza Sharif** and **Heather Florio**, **Dr. Tony Buffington**, and **Dr. Alexandra Milspaw**.

Watch videos of educational content at bit.ly/ICAExpertVids.

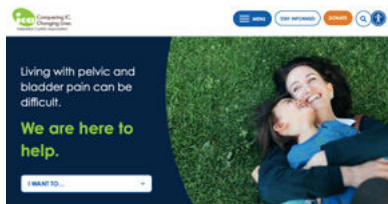
It's not too late to support *Step Up for IC/ BPS*! Visit bit.ly/ICASStepUp22, or to learn more about how to start an IC/BPS awareness walk in your own community, visit ichelp.org/walk-for-an-ic-cure/.

4TH ANNUAL CARTERSVILLE, GA STEP UP FOR IC/BPS WALK RAISES \$4,700

Dr. Jeffrey Proctor and his team at **Georgia Urology** hosted the fourth annual Cartersville, Georgia, *Step Up for IC/BPS – ICA Awareness Walk* on Saturday, September 24. Thanks to dedicated and passionate participants and donors, the event raised over \$4,700.

We would like to extend our gratitude to the event sponsors who helped make the 2022 awareness walk event a success: **Georgia Urology** and **Dr. Jeffrey Proctor**, **West Coast Mint** and **180° Medical**. Shout out to our top individual fundraiser, **Aubrey Williamson**, and to our top team fundraiser **The Stream Team**—we are so grateful for your support!

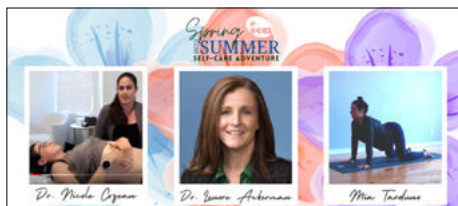
ICA LAUNCHES NEW WEBSITE



ICA announced the launch of its new website at ichelp.org. We hope you find our new website to be more user-friendly and easier to navigate, with access to resources and information about IC/BPS, as well as ways to get involved.

ICA'S SPRING INTO SUMMER SELF-CARE ADVENTURE NOW AVAILABLE TO ALL!

ICA held a **Spring into Summer Self-Care Adventure**, a free virtual and interactive five-day self-care journey, during which more than 400 participants earned points by completing self-care activities and raising critical funds and awareness about IC/BPS.



The videos are now available to the entire IC/ BPS community at bit.ly/SelfCareVids. They include PT Self-Treatment at Home, **Dr. Nicole Cozean**; Desert Harvest: Research Interview with **Dr. Lenore Ackerman** and **Heather Florio**; **Inspire Online Support Community**: Bladder Health Survey; Trauma-Informed Yoga Class with **Mia Tarduno**; Living Well with IC/BPS: The Results of the IC Hope Study; ICA's Online Support Groups; and Mindful Journaling: Share Your Thoughts with Mindful.

ICA BOARD MEMBER REPRESENTS IC/BPS COMMUNITY AT AUA BLADDER HEALTH ALLIANCE

ICA Board Member and IC/BPS patient **Claudia King** served as a panelist for a women and bladder health session during the American Urological Association's Bladder Health Alliance Roundtable. During the AUA event, King discussed how difficult it is for a woman to get a diagnosis of IC/BPS and other barriers to care and stigma associated with the condition.

IC/BPS IN NATIONAL MEDIA

To spread awareness of IC/BPS, it is essential that people are exposed to it in the media. ICA highlighted examples of national media coverage, including:

Bachelorette Star Diagnosed with IC/BPS

Angie Kent, former star of the *Bachelorette* TV series, revealed that she has been diagnosed with IC/BPS. The 34-year-old, who starred in the Australian version of the show, said on her Instagram account that "I have a new diagnosis, interstitial cystitis.... This is a marathon, not a sprint." Other IC/BPS patients responded, offering support and words of advice. Read Kent's Instagram post at bit.ly/IC-Kent.

IC/BPS Goes Viral on TikTok



Breanne Rodgers has more than 450,000 followers on the TikTok viral video platform, so when the 21-year-old Alabamian posted a video from her car about her yearlong experience trying to get diagnosed

after having "constant UTIs," more than 1.1 million people wound up viewing it. Hundreds of other IC/BPS patients also responded with advice on diet and support. "As painful as it is, it's so, so comforting to know other women have this," one said.

View Rodgers' video at bit.ly/TikTok-ICBPS, or read an article about her experience at yhoo.it/3wjMFSF.

Black Health Matters: Meet 'James'

"James" (real name changed for privacy purposes) shared his IC/BPS story with **Black Health Matters** to increase awareness. Read more at

blackhealthmatters.com/personal-bladder-health-story-interstitial-cystitis.

HERE FOR YOU IN 2022 AND BEYOND

ICA continues to serve the IC/BPS community, with many free resources online 24/7 at ichelp.org. They include:

- ICA's IC/BPS Facebook support group
facebook.com/groups/ICBPSGroup/
- ICA's Online Support Community
inspire.com/groups/interstitial-cystitis-association/
- ICA's Facebook page
facebook.com/InterstitialCystitisAssociation
- IC/BPS support group directory
ichelp.org/us-support-groups
- ICA healthcare provider registry
ichelp.org/healthcare-provider-registry
- Ask an IC Question page
ichelp.org/ask-an-ic-question
- Staff and volunteer support at
icamail@ichelp.org or 703-442-2070.

2022 ICA BOARD OF DIRECTORS

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Theda Khrestin

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FINANCIAL STATEMENT

Making the Most of Limited Resources

In 2022, the Interstitial Cystitis Association (ICA) continued its mission as a steward for resources for programs and services that directly support education, advocacy, and research for IC/BPS. A summary of financial statements incorporated in the annual audit report issued by Rogers & Company for the fiscal year ended September 30, 2022 will be available in the "About Us" section of the ICA website, www.ichelp.org.



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