

2023

Annual Report



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Conquering IC. Changing Lives.

Interstitial Cystitis Association

Throughout 2023, 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 • • •

Nearly 40 years after its founding, ICA continues to stand with the more than 12 million people in the interstitial cystitis/bladder pain syndrome (IC/BPS) community. While the times have changed, in 2023, the ICA continued its work to ensure efficient diagnosis and optimal care for people affected by IC/BPS through advocacy, education, and community.

ICA launched *Navigating IC/BPS: Conversations with Experts*, a monthly webinar series which aims to equip individuals with the latest knowledge, insights, and groundbreaking information about IC/BPS. During IC/BPS Awareness Month, our *Pain to Purpose* virtual event included a week of dedicated programs and offerings, a virtual online support group, and opportunities to become involved and spread awareness.

As the only organization representing the interests of IC/BPS patients on Capitol Hill, ICA Board Members, staff, and passionate advocates met with Congressional offices from 16 different states advocating for pivotal research funding and education for the IC/BPS community. We meet regularly with Congressional leaders and policymakers throughout the year to support those affected with this condition.

ICA's efforts to establish a Medical Advisory Council of leaders in IC/BPS healthcare and research will provide medical and scientific expertise to advance the ICA's mission. Along with hosting research webinars and symposiums, ICA was also invited to participate in the International Society for the Study of IC/BPS (ESSIC) annual meeting, allowing us to share the importance of ICA and patient advocacy to a global audience of IC/BPS researchers.

Our work has been recognized with a four-star rating from Charity Navigator, the world's largest and most trusted nonprofit evaluator. But the trust and reputation this top rating recognizes ultimately comes from you—our members, advocates, and supporters. With your help, we will continue to bring together the IC/BPS community to connect, learn, advocate—and hope—for decades to come.

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 ensure efficient diagnosis and optimal care for people affected by IC/BPS through advocacy, education, and community. To learn more, visit ichelp.org/donate.



ICA ADVOCATES ON CAPITOL HILL



ICA continues to be the voice for people living with IC/BPS on Capitol Hill! On Monday, March 6, 2023, ICA Executive Director Lee Lowery and ICA's Washington representative met with staff at eight Congressional Offices, including **Sen. Brian Schatz (D-HI)**, **Sen. Tim Kaine (D-VA)**, **Sen. John Boozman (R-AR)**, **Sen. Jack Reed (D-RI)**, **Rep. Andy Harris (R-MD)**, **Rep. Mario Diaz-Balart (R-FL)**, **Rep. Steve Womack (R-AR)**, and **Rep. Robert Aderholt (R-AL)**.

16 STATES, ONE GOAL: ICA ADVOCACY DAY



ICA's 2023 Advocacy Day took place on April 17. Attendees included ICA board members, staff, and passionate advocates who met with Congressional offices from 16 different

states. The main focus was to advocate for vital research funding and education in the IC/BPS community. This is essential work that can benefit so many individuals who are affected by this condition.

To learn more about ways to educate your representatives about IC/ BPS, visit ichelp.org/get-involved/advocate/.

IC/BPS AWARENESS MONTH PROCLAMATIONS



The ICA created the first-ever IC/BPS Proclamation Proposal to raise awareness about IC/BPS, resulting in official proclamations in Texas and the city of Austin, Colorado and the city and county of Denver, Philadelphia, Illinois, Chandler, Arizona, and elsewhere. The proposal outlines the

steps to submit a proclamation to state and local governments requesting a proclamation honoring/acknowledging IC/BPS awareness in September. The proposal's mission is to increase political awareness of IC/BPS in hopes of sparking interest from the city council and state legislatures regarding the disease and its impact on constituents.

ICA's FY 2023 Legislative 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 healthcare 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 \$50.924 billion in FY 2024.**

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.

- **Continue to include "interstitial cystitis" as conditions eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2024.**

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.

2023 Policy Priorities:

- **Maintain access to chronic pain care medication and protect the patient/doctor relationship with regards to prescriptions.**

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/advocate

• • • 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.

ICA HOSTS WEBINAR FOR RESEARCHERS



On March 22, the ICA hosted a webinar to help researchers understand the Congressionally Directed Medical Research Programs (CDMRP)'s history and its purpose. The webinar also discussed how researchers can apply for awards under the Peer Reviewed Medical Research Program (PRMRP) as part of the fiscal year review cycle for 2023.

During the webinar, the ICA highlighted the success of IC/BPS researchers in receiving funding since IC was first designated as eligible for study in FY 2005. Through the PRMRP, IC/BPS researchers have been awarded over \$21.6 million in research grants. The webinar provided researchers with valuable information and guidance on how to prepare and submit a PRMRP proposal.

ICA RECONSTITUTES MEDICAL ADVISORY COUNCIL

ICA worked during 2023 to reconstitute its Medical Advisory Council (MAC) to provide medical and scientific expertise to advance its mission and support those with interstitial cystitis/bladder pain syndrome (IC/BPS).

Appointed to three-year terms, members of the ICA's MAC will contribute advice and expertise to the current and future work of ICA, meet annually, attend ICA events and fundraisers, and provide educational content in areas in which they have subject matter expertise. Nominations for the MAC were solicited throughout the year, and members of the council were announced in the Spring 2024 issue of *ICA Update* (see p. 3).

GLOBAL CONNECTIONS AT ESSIC



ICA board members attended the 2023 International Society for the Study of Interstitial Cystitis/Bladder Pain Syndrome (ESSIC) meeting, held July 6-8 in New York City.

“ESSIC, which had been quiescent since COVID, is beginning to have a rebirth and some momentum to move forward,” said former ICA Board Member **Robert Moldwin, MD**, ESSIC vice president and 2023 meeting chair.

ESSIC devoted a full session to patient advocacy groups, during which ICA Chair **Laura Santurri, PhD, MPH, CPH** and ICA Board Vice Chair **Claudia King** highlighted how the organization advocates for research funding, provides a community for patients, offers science-based information, and emphasizes the self-management skills so critical to managing IC/BPS. Santurri also urged practitioners to refer patients to ICA. “The sooner they can become part of our community, the better their outcomes will be,” she said.

ICA HOSTS SYMPOSIUM ON MULTIDISCIPLINARY APPROACHES TO PELVIC PAIN



As part of IC/BPS Awareness Month activities, ICA hosted a groundbreaking symposium titled “IC/BPS and Other Forms of Pelvic Pain: A Symposium on Multidisciplinary Approaches” on Saturday, September 23, 2023. The symposium aimed to address the challenges and provide new insights into the diagnosis and treatment of chronic pelvic pain conditions, such as interstitial cystitis/bladder pain syndrome, prostatitis, pelvic floor muscle spasm, and male and female sexual pain.

The ICA would like to thank the experts from The Arthur Smith Institute for Urology, The Katz Institute for Women's Health, and STARS Rehabilitation of the Northwell Healthcare System for sharing their expertise. Distinguished speakers from these organizations included: ICA Medical Advisory Council members **Jennifer Fariello-Moldwin, MSN, MEd, WHNP-BC**, female urogenital and sexual medicine, and **Robert Moldwin, MD**, professor of urology, as well as **Bella Grossman, PhD**, clinical psychologist, **Mary Hughes-Johnson, PT, DPT, PRPC**, board certified clinical specialist in women's health physical therapy, **Adi Katz, MD**, associate professor, **Marina Ruzimovsky, NP-C**, pelvic pain specialist, and **Joel N.H. Stern, PhD**, professor of neurology, surgery, and molecular medicine.

A recording of the symposium is available at bit.ly/ica-symp23.

ICA CONNECTS PATIENTS TO CLINICAL TRIALS

ICA continues to connect patients to relevant clinical trials and research studies. Among them in FY 2023 were three separate research studies seeking patients to evaluate investigational medications—meaning those which are not currently approved for clinical use—for the potential treatment of IC/BPS in women.

One, the OAG1050 study, focuses on a tablet taken once daily before bed (to learn more, visit bit.ly/OAG1050-ICA). Another involves a liquid solution administered as an injection to the bladder (visit ic-bpsstudy.com for details), while the third is evaluating an investigational, foam-based drug designed to inhibit pain receptors in the colon, which may modify pain in the bladder (visit icbpcclinicalstudy.com for details).

ICA SUPPORTS BOSTON CHILDREN'S HOSPITAL DNA AND EPIDEMIOLOGY RESEARCH

As part of its CDC cooperative agreement grant, the ICA partnered with Boston Children's Hospital to develop and disseminate a survey for patients who have been diagnosed with or experienced symptoms of IC/BPS. With the help of the ICA and a grant funded by the National Institutes of Health (NIH), researchers from Boston Children's Hospital discovered that people with IC/BPS were more likely to have rare variants of a specific gene called ATP2C1. While it's not clear whether these connections are coincidental, the findings suggest ATP2C1 is a candidate for future research.

To improve the racial diversity of the cohort, which was 90 percent white, **Catherine Brownstein, MPH, PhD**, worked with the ICA and a collaborator at Morehouse, **Kiwita S. Phillips, MD, FACOG**, an associate professor of obstetrics and gynecology, to identify additional candidates. Researchers also ran an advertising campaign on Boston's subway system to attract more underrepresented patients.

Dr. Brownstein also conducted epidemiology research under a grant from the Centers for Disease Control and Prevention (CDC). One preliminary finding from this work is that underrepresented IC/BPS patients find different symptoms more bothersome than their white counterparts. The ultimate goal is to identify a specific biomarker that can be used to create an IC/BPS-specific diagnostic test—which would speed diagnosis for all patients and help treatment begin before symptoms progress.

• • • EDUCATION • • •

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

NAVIGATING IC/BPS: A NEW MONTHLY WEBINAR SERIES FROM ICA

The Interstitial Cystitis Association (ICA) launched in 2023 a monthly webinar series: **Navigating IC/BPS: Conversations with Experts**. These webinars aim to equip individuals with the latest knowledge, insights, and groundbreaking information from some of the industry's most prominent thought leaders, experts, and practitioners to help empower people living with interstitial cystitis/bladder pain syndrome (IC/BPS).

Among the speakers and topics during the webinar's first year:

April: **David Klumpp, PhD**, *Bacteria as Pelvic Pain Triggers and Potential Therapies*

May: **Robert Moldwin, MD**, *The Pelvic Floor Muscles: Another Possible Source of Pain for the IC/BPS Patient*

June: **Tony Buffington, DVM, PhD**, *Uncovering Social Factors in Chronic Primary Pain Conditions: Lessons from Our Feline Companions*

July: **Jennifer Fariello Moldwin, MSN, MEd, WHNP-BC**, *When Sex Hurts*

August: **Laura Santurri, PhD, MPH, CPH** and **Renee Hetzler, PT, DPT**, *Don't Believe Everything You Read: How to Make Informed Decisions About Your Care*

The continuing series promises to cover a wide range of topics, including the latest in IC/BPS research, physical therapy, diet, mental health, self-care, and much more. Through these webinars, we intend to facilitate interactive and engaging conversations that share best practices and actionable strategies to help people living with IC/BPS.

The registration fee is a minimum donation of \$25. To learn more, visit ichelp.org/navigatingicbps. Recordings of past webinars are available at the ICA Store at ichelp.org/shop.

PAIN TO PURPOSE: IC AWARENESS MONTH 2023



September is IC/BPS Awareness Month, a once-in-a-year opportunity for those passionate about making a difference in the world of IC/BPS. In 2023, the ICA hosted an educational and fundraising event to raise awareness about the condition and identify ways for people living with IC/BPS and their community to find the support they need.

Through a virtual platform, IC/BPS patients had the opportunity to learn, interact, and connect with experts and fellow members of the IC/BPS community, share their experiences, gain new perspectives, and forge valuable connections that will support them on their journey.

The free virtual experience featured topics including:

- A live IC/BPS Support Group with past ICA Board Chair **Barbara Zarnikow**

- Care Partners: **Kristi Ninnemann, MA, MPH, Jenlene Nowak, Eric Zarnikow**
- Advocacy: **Theda Khrestin**, ICA Board member
- Handling the Emotional and Mental Impacts of IC/BPS: **Tacha Kasper, MA, LMFT**, ICA Board member
- Men & IC/BPS: **Samantha Ginsburg, PT, DPT**
- The Pelvic Floor Connection: **Nicole Cozean, PT, DPT, WCS, CSCS**, ICA Board member
- Your Story, My Examination: **Kristene Whitmore, MD**
- IC/BPS & Intimacy: **Jennifer Fariello Moldwin, MSN, MEd, WHNP-BC**, and **Heather Florio**, Desert Harvest CEO

Along with expanding their knowledge and understanding of this challenging condition, participants had the opportunity to build awareness and support by creating a fundraising page or making a donation, joining a diverse community of individuals united by their commitment to raising awareness about IC/BPS. Individual donations up to \$7,500 were matched by the Toth family and SPX Corporation in Charlotte, N.C. ICA gratefully acknowledges our generous IC Awareness Month sponsors, Desert Harvest and Prielief, for their commitment and support.

ICA HOLDS IC/BPS AWARENESS WALK AND SYMPOSIUM IN FLORIDA



ICA partnered with Nova Southeastern University's Institute of Neuro-Immune Medicine, Dr. Kiran C. Patel College of Osteopathic Medicine (KPCOM) to host an IC/BPS Symposium and **Step Up for IC/BPS Awareness Walk** on March 11, 2023, in Clearwater, Florida.

This unique day-long event took place at Nova Southeastern University, with the daylong symposium offered both in person and virtually. It was followed by the Step Up for IC/BPS Awareness Walk. Topics included Diet & IC/BPS, Getting to Know You and Your IC/BPS, Comorbidities and Neuroinflammation, and more. Healthcare providers had the opportunity to receive a certificate of attendance from Nova Southeastern University which could be used for continuing education credit.

Speakers included: **Robert Moldwin, MD, Robert J. Evans, MD, Kristene Whitmore, MD, Theoharis Theoharides, MS, MPhil, PhD, MD, FAAAAI, Kenneth Johnson, DO, FACOG, Nancy Klimas, MD, and Amber Carter** of the ICA Board of Directors.

Together, the events helped ICA raise nearly \$8,000 to allow ICA to continue providing much needed educational events to the IC/BPS community. Thank you to our top fundraisers, **Amber Carter, Linda Salin, and Barbara Zarnikow**. We also are deeply appreciative of our corporate sponsors: **Algonot** (Presenting Sponsor), **Ironwood** (Platinum Sponsor), **West Coast Mint** (Gold Sponsor), and **Prielief and Carzato** (Silver Sponsors).

It's not too late to support ICA educational events! Visit ichelp.org/donate to learn more.

• • • **IMPACT AND FINANCIALS** • • •

HERE FOR YOU IN 2023 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, with more than 5,300 members
facebook.com/groups/ICBPSGroup/
- ICA's Online Support Community, with more than 45,000 members
inspire.com/groups/interstitial-cystitis-association/
- ICA's Facebook page
facebook.com/InterstitialCystitisAssociation
- IC/BPS support group directory
ichelp.org/us-support-groups
- Ask an IC Question page
ichelp.org/ask-an-ic-question
- ICA eNews, a monthly online newsletter
ichelp.org/ica-enews
- Staff and volunteer support
icamail@ichelp.org or 703-442-2070.



FINANCIAL STATEMENT

Making the Most of Limited Resources

In 2023, the Interstitial Cystitis Association (ICA) continued its mission as a steward for resources for programs and services that directly support advocacy, education, and community 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, 2023 will be available in the "About Us" section of the ICA website, www.ichelp.org.

2023 ICA BOARD OF DIRECTORS

Laura Santurri, PhD, MPH, CPH, Board Chair

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