ICA
Conquering IC. Changing Lives.
Interstitial Cystitis Association

2024
Annual Report

Prepared & Presented by

Claudia King, CEO, &
Laura Santurri, COO

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Letter from the CEO/COO

Dear ICA Community,

2024 marked a pivotal moment in the ICA's journey–one that brought you closer to the heart of our mission than ever before. As the only national nonprofit in the United States supporting the IC/BPS community, our work has become even more vital to our community.

For the first time in over a decade, our organization transferred leadership to individuals who truly understand the trials and triumphs of our community. Claudia King and Laura Santurri, both of whom have faced the challenges of living with IC/BPS for over 20 years, stepped into leadership roles and began running the day-to-day operations of the ICA. With Claudia's experience in nonprofit management and Laura's background in IC research and education, the two of us became uniquely positioned to elevate our mission and serve you better.

Laura and Claudia have been dedicated members of the ICA Board of Directors, both having served as Board Chair and Vice Chair. We also each turned to the ICA for support during our own journeys, and now, we are here to guide and support you–whether you are a patient who was newly diagnosed, have lived with IC/BPS for years, or are still searching for answers; whether you are a provider who serves IC/BPS patients and/or conducts research to help find new diagnostic tools, new treatments, and a cure; whether you are a friend, family member, or partner of an IC/BPS patient who is searching for the best ways to help your patient through the life-altering challenges of living with the condition; or, whether you support the ICA in honor or memory of a patient who has touched your life.

We're proud to share a few of the ICA's achievements in 2024 in this annual report. As always, we welcome your feedback and questions. Together, we can ensure that the ICA remains a beacon of hope and the trusted support for all affected by IC/BPS.

Thank you for your unwavering commitment to our community. Your support is more vital than ever, and with your help, we will achieve extraordinary things.

Respectfully,

Your ICA Family
Claudia King (CEO) and Laura Santurri (COO)

About the ICA

The Interstitial Cystitis Association (ICA) was established in 1984 to put a face on all those affected by interstitial cystitis/bladder pain syndrome (IC/BPS). It remains today the only non-profit health association in the United States solely dedicated to improving the quality of healthcare and the lives of people affected by IC/BPS.

Meet Our Staff

CLAUDIA KING
CHIEF EXECUTIVE OFFICER

Claudia resides in Denver, Colorado, with her husband, Lee, and their Pekingese, Buster. She was diagnosed with IC in 2005, just one month before her wedding, and she has always turned to the ICA for support and reliable information. Claudia believes that all patients can be advocates, and she takes the opportunity to speak with every new doctor she sees about IC, its symptoms, and its effects. Claudia has been involved with the ICA for several years, initially as a creator of a patient advocacy toolkit, then as a board member, and most recently as board chair. Claudia has a degree in Business Management and Finance from Guilford College and a background in fundraising, marketing, and nonprofit management. In addition to her role with ICA, Claudia is a guest legal analyst and domestic violence expert on live TV, where she speaks on current court cases and legal news. She also hosts a podcast called Strong Enough, where guests share inspiring stories of overcoming trauma.

LAURA SANTURRI
CHIEF OPERATIONS OFFICER

Laura lives in New Franklin, Ohio, with her husband, Harlan, and seven adopted dogs. She was diagnosed with interstitial cystitis/bladder pain syndrome (IC/BPS) in 2000 but started having symptoms about three years prior, when she was 14 years old. Just before her diagnosis, she stumbled upon the ICA, an organization that quickly became her lifeline. Since that time, she has been engaged with the ICA in various ways, including as a volunteer, board member, and board chair. Laura is passionate about patient education and ensuring that all members of the IC/BPS community have the evidence-based information they need to make the best decisions about their care. Laura has a B.A. in Interdisciplinary Anthropology, an MPH with a focus on disease prevention and health promotion, and a PhD in health education and promotion. In addition to her role with the ICA, she serves as associate adjunct faculty with the University of Indianapolis.

Meet Our Board of Directors

AMBER CARTER-FRAUENHOFER
BOARD CHAIR

Amber has served on the ICA's Board of Directors since 2022. In addition to her work on the board, she also serves as the Liaison to the Medical Advisory Council, represents the ICA at the Global IC/BPS Patient Advocate Group, participates in Peer Reviews, and runs an IC Support Group in the Central Florida area. Amber was diagnosed with IC/BPS in 2005, and as a long time IC patient, Amber has found solace and motivation through engaging with and offering support to other IC patients. She credits the ICA for always providing valuable evidence-based information and resources to navigate the complicated disease. In her spare time, Amber enjoys traveling, reading, property renovation and interior design, cooking, and spending time with her family. She currently resides in Orlando, FL, with her husband (Jesse), dog (Dolce), and two cats (Bella & Esprit). Amber has a Bachelor of Science in Legal Studies from the University of Central Florida and has extensive experience working as Paralegal in civil litigation, municipal law, contracts, and real property.

CALLIE KRAJCIR
BOARD VICE CHAIR

Callie Krajcir is a Registered Dietitian specializing in interstitial cystitis (IC). She has helped over 100 IC Warriors get relief from their symptoms through diet and lifestyle interventions. Callie has a Bachelor's of Science in Nutrition and Dietetics from West Chester University and a Master's of Science in Clinical Dietitics from The University of Rhode Island. Callie has struggled with IC her entire life and currently has her symptoms managed through a holistic approach. She has been a Registered Dietitian for 5 years and during that time decided she wanted to help other IC Warriors get relief from their symptoms and improve their quality of life. Callie is the host of IC You, a podcast focused on raising awareness for IC and interviewing various experts in the field. She is also very active on social media platf.orms like Instagram and Tiktok to share information on IC and raise awareness. Callie currently resides in Pennsylvania with her boyfriend, dog, and 2 cats. She enjoys traveling, taking barre classes, and watching Philly sports teams.

JANELLE FABA
BOARD TREASURER

Janelle Faba is a technology professional who has worked in the Financial Technology (FinTech) industry for 20 years. She has held various senior management roles within the industry and is currently a VP in Information Security for a Fortune 500 FinTech organization. She holds many professional certifications including the Project Management Professional (PMP) and Certified in Risk and Information Systems Control (CRISC) and has a Masters of Science in Information Systems Management (MS-ISM) from ASU. She resides in Arizona with her husband. Together they have six children; two adult children and four living at home. Janelle was diagnosed with IC in 2001 and through her work with the board Janelle hopes to promote awareness of the condition in the medical and general community and to help all patients to find hope and relief.

Meet Our Board of Directors

NATASHA BOSWELL
BOARD MEMBER

Natasha is a Partner in KPMG's Banking and Finance Services practice based in New York and also a long-time IC patient. As a career professional and mother of three daughters, Natasha has struggled with symptoms of the disease for years. Through her work with the Board, Natasha hopes the ICA will continue to promote research and treatments that will help millions of women and men achieve the quality of life they deserve.

SARA COJOCARU
BOARD MEMBER

With over 20 years of experience in the corporate and small business space, Sarah Cojocaru is an Executive Leader, serving as the Vice President of Automotive Operations for Carzato LLC, an innovative digital commerce provider in the automotive technology sector. While focusing on growing her company's operational excellence, Sarah is supported by her loving husband who works in the medical field and their twin children, a son and daughter. Sarah has pushed for patient awareness for many years leading the SouthEast Michigan Interstitial Cystitis chapter from 2012 – 2015. With her desire to help others, Sarah promoted awareness of the group and provided support to over 60+ members in the SouthEast Michigan area.

HOLLY GOODWIN
BOARD MEMBER

Holly earned her Master's in Library and Information Science in 2018 and has since dedicated her career to academic librarianship. Residing with her partner in a small, rural southern town, she is also a passionate advocate for women with chronic pelvic pain, drawing from over 15 years of personal experience with Interstitial Cystitis and the challenges of finding effective treatment. Through her work with the ICA, she aims to empower others with the disease to find effective treatment with greater ease and speed.

Meet Our Board of Directors

SHELLEY KARDON
BOARD MEMBER

Shelley was diagnosed with IC more than 20 years ago and likes to say that she is an "IC Survivor," since she is pain free today. She researched and educated herself about IC and worked with physicians, physical therapists, compounding pharmacies, and a pharmaceutical company to resolve her IC pain. Throughout this journey, she learned how to navigate a complex health issue. Shelley works in the fundraising office of a Philadelphia private university. She holds a BS in Human Behavior and Development and Education from Drexel University, an MA in Liberal Arts from the University of Pennsylvania, and an MS in Library Science from Drexel University. She is an avid reader and enjoys sewing and making quilts. She lives in Philadelphia, PA and Brigantine, NJ with her husband Sean.

DAVID KLUMPP
BOARD MEMBER

Dr. Klumpp received a Ph.D. in Biochemistry, Molecular Biology and Cell Biology from Northwestern University in 1994, studying retinal neuron physiology. After postdoctoral studies in HPV pathogenesis and epithelial biology at Northwestern's Feinberg School of Medicine, he joined the Department of Urology in 1998. He is a Professor of Urology and Microbiology-Immunology in the Feinberg School of Medicine and the Anthony J. Schaeffer MD Professor of Urology.

CHRIS MEENAN
BOARD MEMBER

Mr. Meenan has over 30 years of experience in the biopharmaceutical industry. Mr. Meenan has worked as a senior scientist, leading research and product development focused on peptide based therapeutics for Unigene Laboratories as well as process development and manufacturing technology transfer. Mr. Meenan ultimately took on the role of Director of Business Development, leading licensing initiatives for Unigene. After leaving Unigene, Mr. Meenan consulted for several small and start-up companies in the areas of translational research, CMC and business and corporate development, and continues to function on advisory boards. Mr. Meenan joined Urigen Pharmaceuticals (now Vaneltix Pharma) in 2014 as Vice President of Corporate and Product Development. Vaneltix Pharma specializes in diseases of the lower urinary tract and is currently running clinical trials on its Alenura product for the treatment of painful flares of IC/BPS. Mr. Meenan earned his BS in Recombinant Gene Technology from SUNY Fredonia, MS in Molecular Genetics from Drexel University and an MBA in Marketing from Montclair State University.

Meet Our Board of Directors

ILKA ROSS
BOARD MEMBER

After receiving an interstitial cystitis diagnosis 6 years ago; I developed a strong desire to promote wide spread education on IC in an effort to streamline diagnostic procedures and extend support to my fellow IC patients in the form of advocacy. My expertise is in Operational Management of mental health facilities, with a current focus on the implementation of applied behavioral analysis as treatment for adolescent children with ASD, as well as Chief Operating Officer of New Beginnings Ptg.

AVERY SINGER
BOARD MEMBER

Avery Singer is an artist living and working in New York, NY. She has been honored with solo museum presentations at Museum Ludwig, Cologne (2019); Kölnischer Kunstverein, Cologne (2017); Secession, Vienna (2016); Stedelijk Museum Amsterdam (2016); Hammer Museum, Los Angeles (2015–16); Fondazione Sandretto Re Rebaudengo, Turin (2015); and Kunsthalle Zurich (2014–15). Singer's work is represented in the permanent collections of the Museum of Modern Art, New York; Art Institute of Chicago; Hammer Museum; Whitney Museum of American Art, New York; the Tate, London; and Stedelijk Museum Amsterdam, among numerous others. Singer is a passionate advocate in the field of women's health, having been a chronic pain patient nearly all of her life. In addition to the Interstitial Cystitis Association, Avery Singer serves on the board of her alma mater, the Cooper Union of the Advancement of Science and Art, and philanthropically supports the work of the Endometriosis Foundation of America.

ERIC ZARNIKOW
BOARD MEMBER

Eric Zarnikow is Executive Director of the Illinois Student Assistance Commission (ISAC), a state agency focused on helping to make postsecondary education more accessible and affordable for Illinois families. ISAC provides comprehensive, objective, and timely information on education and financial aid for students and their families–giving them access to the tools they need to make the educational choices that are right for them. Then, through the state scholarship and grant programs ISAC administers, including the state's flagship Monetary Award Program, ISAC can help students make those choices a reality. Eric is a former Associate Administrator at the U.S. Small Business Administration, where he led the Office of Capital Access, responsible for all the agency's programs and operations concerning financial assistance to small businesses, 800 employees and a $90 billion loan and investment portfolio. Prior to his work with the SBA, Eric spent over 25 years in the private sector, including serving as Senior Vice President, Chief Risk Officer and Treasurer at ServiceMaster. Eric serves on several commissions and Boards and is currently a trustee of The College Board, serving on its Executive, Finance and Investment Committees and as chair of its Audit Committee. A certified public accountant, Eric received his bachelor's degree from Iowa State University and MBA from Drake University.

Vision, Mission, & Strategic Pillars

Vision

Conquering IC/BPS. Changing lives.

Mission

The mission of the ICA is to ensure efficient diagnosis and optimal care for people affected by IC/BPS through advocacy, education, and community.

Strategic Pillars

. To fulfill its mission, the ICA pursues three core functions:

- **Advocacy**: By rallying a grassroots network, ICA advocacy efforts empower people affected by IC/BPS around the country and the world, teaching them to become self-advocates for their healthcare needs. In addition, the ICA raises awareness among legislators and government leaders about the need for increased levels of dedicated federal funding for IC/BPS research. The ICA specifically advocates for funding through the Centers for Disease Control and Prevention (CDC), the Department of Defense (DoD), and the National Institutes of Health (NIH) to explore and discover effective treatments and, ultimately, a cure for IC/BPS.
- **Education**: The ICA's educational programs raise awareness of IC/BPS and empower those affected to change lives. In all efforts, the organization serves as a curator and translator of the most current science-based information on the condition. Importantly, the ICA reach extends to healthcare providers; we work to improve professional educational efforts with the aim of ensuring optimal care with dignity for all people with IC/BPS.
- **Community**: The ICA provides support communities for those affected by IC/BPS. These communities are places for fostering connection, sharing experiences, and collective growth/learning. The ICA also serves as a powerful connection between IC/BPS healthcare providers, researchers, and those affected by IC/BPS.

2024 Highlights

Advocacy

In March 2024, the ICA met with Congressional Representatives in Washington, D.C., to share personal stories of IC/BPS and why funding is so important, Our efforts have kept funding for IC/BPS research level and have also kept the condition on the important Peer-Reviewed Medical Research Program list. The purpose of this program is to encourage, identify, select, and manage medical research projects of clear scientific merit that lead to impactful advances in health care of active-duty Service Members, Veterans, military beneficiaries, and the American Public. Inclusion on this list opens up additional funding sources for research that has the potential to profoundly impact the development and implementation of medical devices, drugs, and clinical guidance for specific conditions.

2024 Legislative Priorities

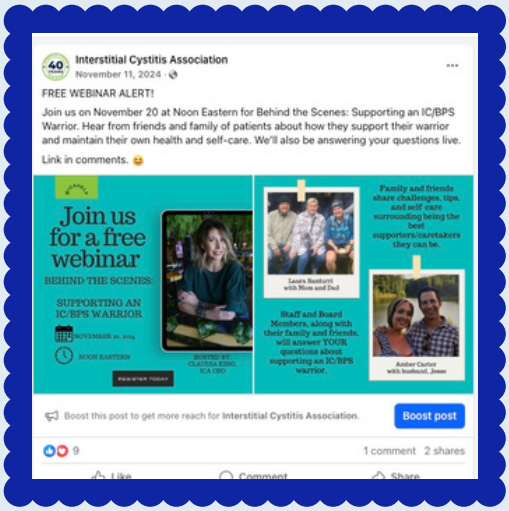
- **Provide $1.5 million for the IC Education and Awareness Program at the Centers for Disease Control and Prevention (CDC) in FY 2025.** This program promotes public awareness of IC through education for health care providers and the public.
- **Include "interstitial cystitis" as a condition eligible for study through the Department of Defense Peer-Reviewed Medical Research Program (PRMRP) for FY 2025.** IC is becoming increasingly prevalent among veterans and is associated with post-traumatic stress disorder.
- **Work with your colleagues to provide the NIH with at least $51.3 billion in fiscal year (FY) 2025** to fully capitalize on research projects that will expand and advance IC research.
- **Support the Advancing Research for Chronic Pain Act of 2023 (S. 2922/H.R. 7164).** High-quality data is necessary to identify trends, risks, and consequences of pain and to inform interventions aimed at improving care and patient outcomes and reducing costs to the US healthcare system.

The 2024 IC Awareness Month Proclamations were a success!

We're thrilled that proclamations were secured in several states and cities, including Texas, Oklahoma, Louisiana, Georgia, Ohio, Maryland, Connecticut, Virginia, New Jersey, Illinois, and Colorado, as well as Orlando, Florida, and Denver, Colorado. These efforts make a difference in increasing visibility and understanding of the condition. This success sets a strong foundation for future advocacy and awareness initiatives.

2024 Highlights

Education



Expert Webinar Series: This year, we hosted 10 webinars covering critical research and treatment discussions, engaging 475 patients and supporters.

ICA Update Publication: Our triannual publication kept patients informed on vital topics and helped combat feelings of loneliness and isolation. In 2024, over 3,000 patients received a copy of our award-winning periodical, providing them with meaningful education on IC/BPS and related subject matter.

The **ICA website** has welcomed more than 2.4 million visitors this year, affirming our role as the trusted resource for reliable information.

Community

In response to feedback from the community during a webinar, the ICA created a new online space for those who support IC/BPS patients. The brand new **ICA Group for Patient Supporters** was started in November 2024.

This new group exists alongside our **ICA IC/BPS Support Group,** which flourished to over 6,100 members in 2024, and our **Inspire online support community**, with over 45,000 members. Both serve to create vibrant and safe spaces for sharing experiences and offering support.

Through our primary ICA page on Facebook, we were also able to provide supportive and educational content, meant to engage and inform our community.

Impact & Financials

HERE FOR YOU IN 2024 AND BEYOND

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

- ICA IC/BPS patient support group
- ICA group for IC/BPS patient supporters
- ICA Inspire online support community
- ICA Facebook page
- IC/BPS support group directory
- IC/BPS healthcare provider directory
- Ask an IC Question page
- ICA eNews, a monthly online newsletter
- Staff and volunteer support
  - Email: icamail@ichelp.org
  - Call: (720) 515-1411

AS A DONOR, YOU CREATED THE FOLLOWING IMPACT TO THE IC/BPS COMMUNITY IN 2024:

- Our monthly eNews reached an audience of over **250,000** patients, providers, and patient supporters
- Over **300** submissions were processed through our "Ask an IC/BPS Question" web form
- **197** IC/BPS patients provided information in our annual survey to help guide our offerings and direct our advocacy efforts
- More than **80** patients received telephone support from volunteers, at no charge

FINANCIAL STATEMENT

Making the Most of Limited Resources

In 2024, the 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, 2024, is available in the "About Us" section of the ICA website.

Contact Us

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