Throughout 2017, the Interstitial Cystitis Association continued its mission of advocacy, research, and education. ICA works to make the lives of those suffering from IC more manageable, and to engage policymakers and the medical community for better diagnosis, treatment, and research towards an eventual cure.

FROM THE EXECUTIVE DIRECTOR

In 2017, the Interstitial Cystitis Association (ICA) continued its four decades of work serving the more than 12 million Americans who suffer from interstitial cystitis (IC). ICA works to make the lives of those suffering from IC more manageable, and to engage policymakers and the medical community for better diagnosis, treatment, and research towards an eventual cure.

Throughout the organization’s history, ICA has maintained a consistent focus on advocacy, research, and education. To ensure that IC patients remain a priority in government funding, ICA continued its strong presence on Capitol Hill, at the National Institutes of Health, and with policymakers involved in broader issues involving clinical trials and chronic pain.

We continue to support important research towards better treatments for IC patients, including our participation in a groundbreaking study leading to the development of a new urine biomarker for the diagnosis of IC. And outreach efforts such as our ongoing presence at the American Urological Association (AUA) Annual Meeting and efforts to engage the public and media continue to help ensure that physicians, patients, and the public have a richer understanding of IC and its impact on patients’ lives.

The organization continues to navigate financial challenges to meet its mission to support research, education, advocacy, and hope. But the ICA also continues to strengthen its governance and operations, including the continued growth of our Board of Directors, now chaired by Irma Rodriguez.

Our commitment to improve the outlook for those with IC remains unchanged. As ICA’s Executive Director, I, along with the Board of Directors, ICA staff, and the IC community as a whole thank you for your continued support—now, and in the years to come.

Lee K. Lowery, MPA, CAE
ICA Executive Director

Give Hope, Change Lives

Your support helps ICA provide advocacy, research funding, and education to ensure optimal care and dignity for people affected by IC. To learn more, visit www.ichelp.org/donate.
ICA advocates for the needs of the 12 million Americans with interstitial cystitis, as well as those of the healthcare providers, researchers, and others who work to improve the lives of IC patients. We also empower people with IC to advocate for themselves and to ensure we maintain momentum and awareness of the condition and those who suffer from it.

ICA LEGISLATIVE PRIORITIES AND CAPITOL HILL VISIT

ICA made its annual visit to Capitol Hill on May 2, 2017. ICA’s 2017 legislative priorities included:

RESPONSIBLE PAIN MANAGEMENT

• Support the National Pain Strategy (NPS). Access to chronic pain care medication is a priority for the IC community.

NATIONAL INSTITUTES OF HEALTH (NIH)

• Provide $36 billion for NIH. Strengthening the nation’s biomedical research enterprise through NIH fosters economic growth and sustains innovations that enhance the health and well-being of the American people.

• Support the NIH research portfolio on IC. The cause of IC is unknown, there are no definitive diagnostic tools available to clinicians, and there is no cure. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) leads the NIH research portfolio with 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.

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

• Provide $1 million for the CDC IC Education and Awareness Program, which 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 to increase awareness, diagnosis, and proper treatment.

DEPARTMENT OF DEFENSE (DOD) PEER-REVIEWED MEDICAL RESEARCH PROGRAM

• Include interstitial cystitis in the Peer-Reviewed Medical Research Program. 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.

AFFORDABLE CARE ACT REFORM

• Preserve basic patient protections from the Affordable Care Act, including:
  • Prohibiting insurer discrimination against pre-existing conditions
  • Allowing young adults to stay on their parents’ insurance until the age of 26
  • Establishing reasonable maximums for out-of-pocket costs
  • Prohibiting annual and lifetime caps on insurance coverage

ICA SHARED YOUR VOICE WITH THE FDA

ICA staff, board members, and IC patients spoke at the Open Public Hearing (OPH) segment of the December 7, 2017, meeting of a U.S. Food and Drug Administration (FDA) committee considering clinical trial criteria for IC patients.

During the hearing, the FDA Bone, Reproductive and Urologic Drugs Advisory Committee discussed appropriate patient selection criteria and clinical trial design features, including acceptable endpoints, for demonstrating clinical benefit for drugs intended to treat interstitial cystitis (IC) and bladder pain syndrome. The committee also discussed whether bladder pain syndrome and IC reflect overlapping or different populations, and whether it is appropriate to assess efficacy in the same way for both conditions.

In its position statement representing the IC community, ICA representatives urged the FDA committee to do the following:

• Keep a simple and broad definition of the condition, which we believe is necessary to capture and study as much as possible of this underserved population;
• Consider IC and BPS as overlapping conditions that warrant similar processes for assessing treatment efficacy; and,
• In the design of clinical trials, 1) to the extent possible, include equal amounts of men and women in clinical trials, 2) measure quality of life, pain, and sexual dysfunction as important indicators of the efficacy of a treatment, and 3) document adverse effects in a detailed manner and in a way that recognizes that even “mild” side effects can be significant for patients living with IC.

At the conclusion of the day, the committee voted unanimously to include both IC and BPS patients in the same clinical trials, as recommended in ICA’s position statement.


BECOME AN IC ADVOCATE

Learn how to become an IC Advocate with ICA’s toolkit, which includes information about communicating with Congressional representatives and their offices.

Visit www.ichelp.org/advocacy-for-those-affected-by-interstitial-cystitis/.
ICA funds pilot research projects, advocates for government funding dedicated to IC research, and helps keep the research focused on patients by serving on research steering committees and panels.

DISCOVERY OF BIOMARKER FOR IC DIAGNOSIS

Researchers in the urology department at Beaumont Hospital in Royal Oak, Michigan, collaborated with ICA to use social media to recruit research volunteers for a study leading to the development of a new urine biomarker for the diagnosis of IC.

The social media research exceeded expectations. Within just two weeks, 454 women and men from 46 states participated in the study, watching a YouTube video, completing an online survey, and providing urine samples. “IC is ideal for social media research,” says Kenneth Peters, MD, Beaumont’s chief of urology. “The IC community is a motivated patient group because of their poor quality of life. They are relatively younger compared to patients with other chronic diseases; as such, they may be more comfortable and familiar with the internet and social media.”

Analysis of the samples from qualified participants led to the discovery of three proteins that were highly statistically different for research participants with IC with Hunners ulcers versus those without them. These results were then used in a machine-learning program to accurately classify patients with the disease. “Our goal was to develop a simple urine-based test that identifies IC patients with bladder pain syndrome who have ulcerative IC and a bladder permeability defect,” says Laura Lamb, Ph.D., urology research scientist at Beaumont. “The test had to be developed and validated in a large number of samples collected beyond the referral area of our single academic medical center.”

The research was supported with funding from the Taubman Family through the Taubman Interstitial Cystitis Research Program.


ICA AT THE 2017 AUA ANNUAL MEETING

ICA again represented the interests of IC patients at the American Urological Association (AUA) Annual Meeting, an event that draws the largest gathering of thousands of urologists from around the world.

ICA hosted a supporter recognition reception to honor ICA donors, ICA corporate partners, IC researchers, the ICA Medical Advisory Board, and members of the ICA Board. This informal gathering of over 50 individuals gave ICA the opportunity to thank, connect, and reconnect with those whose passion is to improve IC patients’ lives and who help make ICA’s work possible.

ICA also participated in AUA’s Patient Advocacy Hub, which gave ICA Board Member Barb Zarnikow and ICA Executive Director Lee Lowery the opportunity to meet and speak with numerous attendees and share the voice of IC patients. Barb and Lee also presented “What Patients Want Their Doctors to Know About Living With IC” to urologists who visited the Patient Advocacy Hub. Survey participants from ICA’s Facebook community provided the patient’s voice in the presentation.

ICA was represented at the AUA poster session, where the IP4IC study, which was authored by the Beaumont Health System with the collaboration of ICA and IC patients across the country (see previous item), won best poster.

ICA’S 2017 IMPACT

ICA Website
123 support groups
771,444 unique visitors
2,766,451 pageviews

ICA Online Support Community
10,307 users
1,388 discussions

ICA Healthcare Provider Registry
1,500 providers included

ICA eNews
44,463 subscribers

ICA on Facebook
34,000+ page likes
6.3 million total reach

ICA Advocacy
28 members of Congress heard from ICA Staff and volunteers

For a full infographic, visit www.ichelp.org/ica-2017-impact/
ICA arms patients, healthcare providers, caregivers, researchers, and the general public with objective and up-to-date information about IC.

ICA ATTENDS GRÜNENTHAL U.S. PATIENT DAY SYMPOSIUM

ICA Executive Director Lee Lowery and Board Member Jane Elsten, MD, represented the IC community at the U.S. Patient Day Symposium hosted by Grünenthal in June. The aim of the Symposium was to identify issues of concern to the pain community and areas of mutual interest between Grünenthal and patient organizations like ICA. In particular, Grünenthal wishes to bring a greater understanding of the experience of people with pain and their caregivers into its clinical development program. ICA was joined by 12 other patient advocacy groups that struggle with chronic pain. Participants spent the day describing their experiences in order to map the commonalities, differences, and unmet needs in the pain experience. This is the first year that ICA has been invited to this annual event because Grünenthal has taken a new interest in helping IC patients. We look forward to future collaboration.

ICA RELEASES VIDEO ON LIVING WITH IC

ICA released a video that brings awareness to the difficulties faced by patients with interstitial cystitis/bladder pain syndrome (IC/BPS) and guides healthcare providers and patients in working collaboratively to ease some of these struggles. Entitled “Living with IC/BPS,” the video was developed as part of Bladder Health Awareness Month (see left). It can be viewed at http://icbpstips.com, which also features Bladder Health Awareness Month materials from ICA, including tip sheets for healthcare providers and patients with IC/BPS.

Featured in the video were Amy Macnow, a patient with IC/BPS who has been dealing with the condition for several years, and Dr. Lenore Ackerman, a urologist with Cedars-Sinai Medical Center in Los Angeles.

The video and tip sheets were developed in partnership with Aquinox Pharmaceuticals Inc. as part of its efforts to bring attention to the needs of patients with IC/BPS and provide tools to enhance the dialogue between health care providers and patients.

ICA DIGITAL AWARENESS PROGRAM

As part of an education and awareness grant from the Centers for Disease Control and Prevention and in conjunction with Cedars-Sinai Medical Center, ICA conducted a targeted public education and outreach effort focused on the IC patient population. Patient outreach focused on digital media, including Facebook, Instagram, Twitter, and WebMD.

IC IN THE NEWS

Among the national media outlets which brought greater awareness to IC in 2017:

- Reader’s Digest (12 Signs You Might Have Interstitial Cystitis, www.rd.com/health/conditions/interstitial-cystitis-symptoms/)
- WCIU Chicago (https://youtu.be/uwKmtvUzl8s)
MAKING THE MOST OF LIMITED RESOURCES

As the organization continues to face financial challenges to meet its mission to support research, education, advocacy, and hope, 2017 was a challenging year for ICA. Nonetheless, the association continued its mission as a steward for resources for programs and services that directly support education, advocacy, and research for IC. The following is a summary of financial statements incorporated in the annual audit report issued by Rogers & Company for the fiscal year ended September 30, 2017. The complete financial statements and notes are available to view in the About Us section of ICA's website, www.ichelp.org.

STATEMENT OF ACTIVITIES
For the Year Ended September 30, 2017

REVENUE
- Contributions $421,011
- Grants $72,108
- Industry Publication Sales $30,151
- Media Campaign $19,500
- Publication Sales $6,979
- Interest Income $758
- Total Revenue $550,507

EXPENSES
- Program services:
  - CDC Cooperative Agreement $90,993
  - Research $112,770
  - Advocacy $130,242
  - Education $239,510
  - Total program services $573,515
- Supporting services
  - General and administrative $59,561
  - Fundraising $137,052
  - Total supporting services $196,613
- Total expenses $770,128
- Change in Net Assets from Operations ($219,621)
- Change in Net Assets ($317,116)
- Net Assets, beginning of year $393,746
- Net Assets, end of year $174,125

2017 ICA BOARD OF DIRECTORS
- Tony J. Tyler, Chair
- Irma Rodriguez, Vice Chair
- Rick Lufkin, Treasurer
- Barbara Zarnikow, Past Chair
- Eric Zarnikow, MBA, CPA, Past Chair
- Gina M. Barbarotto, MS, MBA
- Nicole Cozean, PT, DPT, WCS, CSCS
- Jane Elsten, MD
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- Paula Maxwell
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- Laura Santurri, PhD, MPH, CPH
- Dan Vickery, PhD