INTERSTITIAL CYSTITIS ASSOCIATION

2016 ANNUAL REPORT

Conquering IC. Changing Lives.
Throughout 2016, 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 2016, ICA continued its four decades of work serving the more than 12 million Americans who suffer from interstitial cystitis (IC). While much has changed since ICA's founding in 1984, our commitment to improving the outlook for those with IC remains the same.

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 chronic pain. Through the ICA Pilot Research Program and a partnership with the American Urological Association Urology Care Foundation, we continue to support important research towards better treatments for IC patients. And outreach efforts such as our ongoing presence at the AUA Annual Meeting, IC-friendly events in communities across the country, and a new approach to diet are helping ensure physicians and patients remain abreast of what works best for IC patients.

We remain challenged by the end of support from the Centers for Disease Control and Prevention (CDC) that funded critical work in IC education and awareness for nearly a decade. But recent efforts to strengthen the organization, including the continued growth of our Board of Directors, have placed ICA on a stronger footing to face the future.

As ICA’s new Executive Director, I, along with the rest of the organization’s staff, its Board of Directors, 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
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 VISITS CAPITOL HILL, HOSTS CALL-IN DAY**
ICA made its annual visit to Capitol Hill on April 19. ICA's legislative priorities for 2016 included:

- Supporting funding the National Institutes of Health at $34.5 billion for fiscal year 2017
- Continuing inclusion of interstitial cystitis in the Department of Defense Peer-Reviewed Medical Research Program
- Supporting the continued funding of the Centers for Disease Control's IC program and provide the program with $1 million in FY 2017 to enhance public education and awareness activities
- Ensuring continued support for chronic pain sufferers. While the IC community is aware that combating opioid abuse is a priority for Congress, policymakers should remember that patients with chronic pain need access to appropriate treatment while also addressing societal issues.

ICA's National Call-in Day was held simultaneously for advocates who weren’t able to join the association and its supporters on the Hill. Advocates from across the country emailed, called, and posted on social media in support of the IC community.

**ICA DISCUSSES IC AT NIH**
On October 6, Robert M. Moldwin, MD, FACS, and a member of the ICA Board of Directors and ICA Medical Advisory Board, and Andy Schwarz, ICA Communications Director, discussed IC with scientists and researchers at the National Institutes of Health (NIH).

Representatives from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Office of Pain Policy at the National Institute of Neurological Disorders and Stroke (NINDS) provided research and scientific updates and discussed programs that will help people with IC such as the Multi-Disciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) and the National Pain Policy. The group also discussed ways that ICA could collaborate with NIDDK and NINDS to educate and support the IC patient community, and ICA is pleased that IC remains a priority for NIH.

**ICA REPRESENTS CHRONIC PAIN PATIENTS IN SENATE BRIEFING**
On June 16, ICA Board of Directors member Jane Elsten, MD, participated in a Senate briefing panel on preserving chronic pain patients' access to medicine. The roundtable discussion was hosted by the American Cancer Society Cancer Action Network and the Alliance to Prevent the Abuse of Medicines and included patients, advocates, and healthcare professionals who shared their experiences and policy recommendations involving access to opioids for those with chronic pain conditions.

The open discussion with Senate staff focused on the importance of preserving patient access to pain medications when appropriate, as policymakers work to adopt new policies to deter opioid abuse and misuse. ICA is giving IC patients a voice in this public policy debate to help ensure the issue is addressed in a balanced way that recognizes the need for individuals with chronic pain to maintain access in order to work, live independently, and enjoy a better quality of life.
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.

ICA SELECTS TWO 2016 PILOT RESEARCH PROGRAM RECIPIENTS

In 2016, ICA provided two researchers with one-year, $50,000 grants funding novel and useful basic, clinical, or translational research studies that attempt to solve the many questions of IC.

Lori Birder, PhD, of the University of Pittsburgh is a professor of medicine and pharmacology and chemical biology at the University of Pittsburgh School of Medicine. With ICA Pilot Research Program funding, Dr. Birder’s basic research study, *Role of Mitochondria in Interstitial Cystitis*, will further investigate recent evidence that supports the view that mitochondrial dysfunction may play an important role in the pathology of the disease. Her team will examine how mitochondrial dysfunction in a rodent model may have implications for how stress-resultant changes in mitochondrial function in bladder tissue may exacerbate IC symptoms.

Jason Kutch, PhD, of the University of Southern California is an assistant professor in the Division of Biokinesiology and Physical Therapy at the University of Southern California. A board member of the International Pelvic Pain Society. Dr. Kutch is a co-investigator in the NIH-funded Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network, with a particular focus on understanding brain network mechanisms of altered pelvic floor muscle control in individuals with chronic pelvic pain.

Entitled *Cortical Neuromodulation to Reduce Symptoms of Interstitial Cystitis/Painful Bladder Syndrome*, Dr. Kutch’s study will focus on a treatment called transcranial magnetic stimulation (TMS) to see if it can be used to effectively help treat IC. TMS uses a magnetic field to activate brain areas non-invasively, and has been an important treatment for depression. Dr. Kutch’s research will help determine whether TMS can help treat IC by helping other treatments work better.

ICA-AUA/UROLOGY CARE FOUNDATION IC RESEARCH SCHOLAR RECIPIENTS

The Urology Care Foundation (UCF), the official foundation of the American Urological Association (AUA) and ICA named two recipients of the IC Research Scholar Awards. Selected following a rigorous peer review process, the award recipients are both exceptional early-career investigators.

Henry Okafor, MD, received a one-year research award for his project, *The impact of tissue regeneration on rodent models of interstitial cystitis/Painful Bladder Syndrome (IC/PBS)*. The project will elucidate the impact of a recently developed drug for inflammatory bowel disease on reversing IC-like functions in a rat model. If successful, this new therapy could be translated to clinical trials and potentially bring relief to IC patients. Dr. Okafor’s research will be conducted at the Cleveland Clinic under the mentorship of Margot Damaser, PhD, and Daniel Shoskes, MD, who say that the research plan is based on a new model of IC which is more physiologically relevant than previous models.

Haeyeong Lee, PhD, received a two-year research award for *Molecular and functional characterization of PDGFRα+ cells in CYP-induced interstitial cystitis*. Her research will further characterize a novel interstitial cell type, PDGFRα+ cells, that play a functional role in the detrusor muscle layers of the bladder. The project will determine how these cells participate in regulating detrusor excitability in cyclophosphamide (CYP)-induced detrusor overactivity in order to better understand bladder overactivity in IC.

A member of the physiology and cell biology department at the University of Nevada, Reno, Dr. Lee’s research will be conducted at the University of Nevada, Reno under the mentorship of Sang Don Koh, PhD, who believes that the research could ultimately lead to new venues for the treatment of overactive bladder.

ICA THANKS ITS DONORS

We would like to recognize our supporters. Please go to www.ichelp.org/ICA-Donors to see the list of donors who give $100 or more.
ICA arms patients, healthcare providers, caregivers, researchers, and the general public with objective and up-to-date information about IC.

**IC PLATE™ REFOCUSES DIET ADVICE FOR IC PATIENTS**

For years, IC patients have known that what they eat can make a big difference in their IC symptoms, and the American Urological Association lists diet modification as a first-line treatment for IC. Up until now, the standard non-scientific “IC diet” has focused almost exclusively on a long list of foods to avoid, to the point where many patients sacrifice nutrition or become afraid to eat.

To focus on what you can eat instead of what you can’t, ICA worked with Medical Advisory Board Member Barbara Shorter, EdD, RD, CDN, and former ICA Executive Director Barbara Gordon, RDN, LD, to explain the science behind IC and diet while also giving in-depth information on topics such as:

- Kicking the caffeine habit
- How to do an elimination diet
- The best IC-friendly foods and supplements for overall health

To help patients with IC-friendly meal planning, ICA developed information on how to build a healthy IC Plate™. To learn more, visit ICA’s diet section at www.ichelp.org/interstitial-cystitis-and-diet.

**ICA AT AUA ANNUAL MEETING**

As part of fostering IC awareness and education for healthcare providers to help ensure early diagnosis and optimal care for IC patients, ICA participated in the 2016 American Urological Association (AUA) Annual Meeting, the largest gathering of urologists from around the world.

ICA once again participated in the AUA’s Patient Advocacy Hub, providing numerous attendees with information about IC and ICA. Members of the ICA Board of Directors and ICA President Emeritus Vicki Ratner, MD, also made numerous new connections with urologists from across the globe.

An educational highlight was a panel discussion by four researchers who discussed the findings of the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) and the implications for urologists and their patients. A 10-year study of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), MAPP is shedding new light on chronic pelvic pain disorders and the comorbid conditions that many also suffer from, including IBS, fibromyalgia, and chronic fatigue syndrome. The panel was moderated by Robert Moldwin, MD, member of the ICA Board of Directors and Medical Advisory Board and co-chair of the MAPP Steering Committee. An analysis of the first five years of MAPP data collected is indicating how clinical care may be changed and the direction of future research studies that will ultimately result in better patient care.

ICA also hosted a meet-and-greet reception for members of the ICA Board of Directors and Medical Advisory Board, MAPP researchers, ICA Pilot Research grant recipients, representatives of international IC organizations, ICA Corporate Partners, and donors. This informal gathering of more than 60 individuals gave ICA the opportunity to thank, connect, and re-connect with many individuals whose life work is to improve IC patients’ lives and who help make ICA’s work possible.

**EVENINGS OF IC-FRIENDLY FOOD AND FUN IN DC AND CHICAGO**

To foster awareness of IC, ICA hosted two evenings of IC-friendly food and fun in Illinois and Washington, D.C.

In April, ICA supporters were invited to a free event at Sur La Table in Skokie, Illinois, that featured professional chef Mitchell Jamra instructing participants on preparing an IC-friendly meal, and David Klumpp, PhD, of Northwestern University sharing recent discoveries in IC research.

In September, ICA hosted a similar event at Sur La Table in Alexandria, Virginia, featuring Chef Lindsey Leopold and Dr. Chris Mullins of the National Institutes of Health sharing the recent discoveries in IC research. Attendees also had the opportunity to meet with members of the ICA Board of Directors, staff, and other IC patients at both events.

**ICA OUTREACH, BY THE NUMBERS**

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<th>ICA Website:</th>
<th>ICA Online Support Community:</th>
<th>ICA Email Blasts:</th>
<th>ICA on Facebook:</th>
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<td>727,129 unique visitors</td>
<td>5,314 users</td>
<td>110 email blasts</td>
<td>503 posts</td>
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<td>2.8 million pageviews</td>
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MAKING THE MOST OF LIMITED RESOURCES

Following the end of support from the Centers for Disease Control and Prevention (CDC) that has funded critical work in IC education and awareness for nearly a decade, 2016 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, 2016. 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, 2016

### REVENUE

- Contributions $427,656
- Industry Publication Sales $42,500
- Publication Sales $12,202
- **Total Revenue** $482,358

### EXPENSES

#### Program services:
- Research $106,702
- Advocacy $135,925
- Education $341,112
- **Total program services** $583,739

#### Supporting services:
- General and administrative $94,886
- Fundraising $123,000
- **Total supporting services** $217,886

**Total expenses** $810,625

### SUPPORTING SERVICES

- **Change in Net Assets from Operations** ($319,267)
- Investment income $2,151
- **Change in Net Assets** ($317,116)
- Net Assets, beginning of year $710,862
- Net Assets, end of year $393,746

ICA
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Interstitial Cystitis Association

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www.ichelp.org