The Interstitial Cystitis Association entered its fourth decade in 2015 with a renewed focus on its mission of advocacy, research, and education. ICA continues to work to make the lives of those suffering from IC more manageable, and to engage the medical community in better diagnosis, treatment, and research towards an eventual cure.

In 2015, ICA continued to work on behalf of the more than 12 million Americans who suffer from interstitial cystitis (IC). Through education, advocacy, and continued research, we are making continued strides towards improving the lives of those with IC and, ultimately, a cure.

Over the past year, we amplified our presence on Capitol Hill with a nationwide call to action. We forged new coalitions with organizations serving the chronic pain community and worked to represent the concerns of IC patients in the new National Pain Strategy, which promises to change the conversation about chronic pain and its impact on society. Through partnerships with the Urology Care Foundation and the American Urogynecologic Society, we expanded our support to researchers working to better diagnose and treat IC. And we continued to ensure that the medical and patient community have access to up-to-date information about diagnosing, treating, and living with IC.

Our ongoing efforts to strengthen ICA continue with the continued growth of our Board of Directors, along with new funding strategies to address 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.

As ICA enters its fourth decade of service, 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 Bryan Claassen, CAE
ICA Executive Director

SUPPORTING ICA, IN MANY WAYS

ICA’s donor recognition program provides a wide range of benefits and a greater variety of support options to its constituents, including free online access to ICA brochures and past issues of ICA Update.

Go to www.ichelp.org/donate to learn more.
ICA remains true to its mission to advocate for the needs of people 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 for the more than 12 million Americans affected by IC.

ON THE HILL, AND NATIONWIDE

Members of the ICA Board of Directors, ICA staff, and IC patient advocates brought the voices of the more than 12 million men, women, and children with IC to Capitol Hill in 2015. Over two dozen Congressional offices representing nine states were educated about the needs of IC patients everywhere and were asked to support the following in the fiscal year 2016 budget:

- Overall funding for the National Institutes of Health (NIH) at a level of $32 billion and investments in basic science, disease pathology, and clinical trials on IC.
- Reinstate ICA funding through the Centers for Disease Control and Prevention (CDC) IC Education and Awareness Program.
- Include IC on the list of eligible conditions for study in the Department of Defense (DOD) Peer-Reviewed Medical Research Program in the Defense Appropriations Bill.

In tandem with ICA’s Capitol Hill Advocacy Day, ICA issued a call to action to the IC community to contact their legislators on April 28. The response was enormous and influential! Legislators received numerous calls and emails, and our constituents participated via social media by tweeting and posting words of encouragement on Facebook.

WORKING WITH ALLIED ORGANIZATIONS

ICA continues to expand partnerships with a growing range of allied organizations focused on overlapping chronic pain conditions. Among the highlights of its advocacy work in 2015:

- Digital Advocacy Institute’s First Annual Conference
- International Pelvic Pain Society (IPPS) 2014 Annual Fall Meeting
- Meetings of the National Advisory Council for Complementary and Alternative Medicine (NACCCAM)
- Friends of NIDDK Meeting with NIDDK Director, Dr. Griffin P. Rodgers
- NIH Pathways to Prevention: The Role of Opioids in the Treatment of Chronic Pain workshop findings telebriefing
- Patient Access to Community Treatment (PACT) Coalition
- Consumer Pain Advocacy Task Force (CPATF)
- Pain Care Forum
- MAPP Research Network Steering Committee Meetings
- NIH National Pain Consortium Symposium

NEW COALITIONS FOR CHRONIC PAIN

ICA became a founding member of the National Coalition of Chronic Pain Providers & Professionals (NCCPPP) in February 2015. NCCPPP is a network of health providers, professionals, and organizations dedicated to serving the chronic pain community. Its vision is of a nation where everyone with chronic pain receives optimum treatment, suffering is eased, and healing is routine.

ICA also participated in a national meeting of leaders in federal agencies, academic institutions, policy organizations, patient advocacy groups, and industry to discuss the obstacles and opportunities to implementing the National Pain Strategy, which recognizes chronic pain as the most prevalent public health challenge in the United States. The Pain Action Alliance to Implement a National Strategy (PAINS) National Pain Strategy Collaborators agreed in principle that the chronic pain and addiction communities need to work together to identify and leverage a common ground in order for the plan to move forward. ICA will be part of the ongoing discussions and will keep the IC community apprised of this vitally important work as it progresses.

NEW SOCIAL SECURITY RULING FOR IC

The Social Security Administration (SSA) has replaced its 2002 ruling for establishing interstitial cystitis as a medically determinable impairment (MDI) and determining disability. The new ruling (SSR) takes into consideration descriptions of IC developed by the American Urological Association (AUA) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), neither of which was available when the prior ruling was published. The new SSR is more thorough and less ambiguous and may improve the opportunity for IC to be interpreted as a medically determinable impairment.

The new SSR also provides guidance in specific areas of adjudication and acknowledges that IC patients may suffer from overlapping conditions, which may also assist those with debilitating overlapping conditions that are filing for disability to reach a favorable outcome.

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/AdvocacyToolkit for more.
The 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 PILOT RESEARCH PROGRAM

With the hope of creating a world where IC is a thing of the past, ICA’s Pilot Research Grant program has funded more than 100 IC research programs to date. The one-year awards of up to $50,000 are intended to fund novel and useful basic, clinical, or translational research studies that attempt to solve the many questions of IC.

In 2015, ICA awarded Pilot Research Grants to Kristina Allen-Brady, Ph.D., MSPH, BA, MPT, of the University of Utah, and Pradeep Tyagi, Ph.D., of the University of Pittsburgh.

Dr. Allen-Brady’s research, *A pilot study to identify predisposition genes for interstitial cystitis/painful bladder syndrome*, will investigate the possibility of using genetic testing to identify those at risk of developing IC.

Family history is a leading known risk factor for future occurrence of IC. In his study entitled *Urinary proteases and exosomes as non-invasive biomarkers of interstitial cystitis*, Dr. Tyagi and his research team will investigate the potential of developing a diagnostic test for IC based on molecular signatures of urine.

Both studies are important steps toward better treatment and finding a cure for IC. Their potential to advance the ability of healthcare providers to identify individuals at high risk of developing IC, in conjunction with improvements in prevention, screening, and treatment, have the possibility of dramatically reducing the disease’s impact on the lives of those affected by IC.

ICA-AUGS GRANT

ICA and the American Urogynecologic Society (AUGS) have created a joint research grant of up to $10,000. ICA wishes to congratulate this year’s grant recipient, Ana Charrua Cordeiro, PhD, of Instituto de Biologia Celular e Molecular, Porto, Portugal. Her study, *Sympathetic nervous system dysfunction is a trigger to BPS/IC symptoms development*, proposes to determine if sympathetic nervous system overactivity induces chronic visceral pain and bladder changes similar to the ones observed in BPS/IC patients. The results from this project will help establish a new chronic visceral pain model that may be of use in the future to unveil new effective treatments and biomarkers for the diagnosis and treatment of BPS/IC.

UROLOGY CARE FOUNDATION RESEARCH COLLABORATION

ICA announced two new research awards as part of a new collaboration with the Urology Care Foundation, the official foundation of the American Urological Association:

- A one-year award for an MD (or equivalent degree) investigator working in basic, clinical, or translational research in IC and,
- A one-year award for an MD or PhD (or equivalent degrees) investigator focusing on exploration into fundamental causes of IC and treatments useful in broad populations of patients rather than treatments to relieve only a particular symptom set or the treatment/diagnosis of only a subpopulation of patients.

IC MEDICAL NUTRITION THERAPY ALGORITHM PUBLISHED

The Journal of the Academy of Nutrition and Dietetics published the first-ever evidence-based medical nutritional therapy (MNT) algorithm for dietitians working with IC patients. Treatment guidelines published by the American Urological Association include dietary modification as a first-line intervention, and the manuscript introduces strategies leveraging the unique practice standards of dietitians.

Authors include Barbara Shorter, EdD, RD, CDN, professor of nutrition at Long Island University (LIU) Post, ICA Medical Advisory Board member, and consulting dietitian and researcher for patients with a range of urological conditions at the Smith Institute for Urology, North Shore-LIJ Health System; first-author Barbara Gordon, RDN, LD, former ICA executive director and the only dietitian who served on the IC AUA Guidelines Committee; Alessandra Sarcona, EdD, RD, director of the dietetic internship for LIU Post; and Robert Moldwin, MD, FACS, a member of the ICA Board of Directors and Medical Advisory Board, professor of urology at Hofstra North Shore-LIJ School of Medicine, and physician in charge at the Pelvic Pain Center, Arthur Smith Institute of the North Shore-LIJ Health System.

The MNT algorithm is available on the ICA website at www.ichelp.org/ICDietPressRelease.
ICA’s goal is to arm patients, healthcare providers, caregivers, researchers, and the general public with objective and current information about IC.

**CDC IC EDUCATION AND AWARENESS PROGRAM**

ICA has lost a critical funding source from the Centers for Disease Control and Prevention (CDC) that fueled critical work in IC education and awareness for nearly a decade. Representing nearly 40 percent of ICA’s annual operating income, the CDC funding empowered people with the information they need to be properly diagnosed and treated more quickly by knowledgeable healthcare providers that recognize and properly refer or treat patients with IC. CDC is now redirecting this funding to support an epidemiologic study intended to fill gaps in previous research and enhance understanding of demographic characteristics (race/ethnicity, socioeconomic status, and geographic region) as well as variations in clinical practice and the impact on the outcome of the disease. While ICA supports continued research that results in better treatments and a possible cure for IC, we also recognize the great need for continued education and awareness that helps patients receive earlier diagnosis and access to treatments today.

**ICA EDUCATIONAL PROGRAM FOR HEALTHCARE PROVIDERS**

ICA’s educational program for healthcare providers, Conquering IC: Identification and Management Strategies, was available on MedScape throughout 2015. This continuing medical education (CME) activity was developed for healthcare providers involved in the diagnosis and treatment of IC, including primary care providers, urologists, gynecologists, and emergency physicians. The educational curriculum provided an interdisciplinary audience with comprehensive continuing education on the most current approaches in the diagnosis, treatment, and management of IC, which may translate into better symptom control and improved outcomes for patients. For healthcare providers, this program offered AMA PRA Category 1 Credits and Continuing Education Credits for Nurses (ANCC). As a result of its availability on MedScape, the program has raised the awareness of IC and educated more than 30,000 healthcare providers.

**ICA WEBINAR**

On April 16, ICA hosted a webinar, Creating a Positive Patient-Provider Relationship, led by ICA Board member Joy Selak, PhD, and her healthcare provider, Steven S. Overman, MD, MPH. Drs. Selak and Overman together wrote a book, *You Don’t LOOK Sick! Living Well with Invisible Chronic Illness*, about their shared experience. The free webinar is now available for viewing online (www.ichelp.org/support/virtualpatienteducation).

**ICA @ AUA 2015**

For the second year in a row at the American Urological Association (AUA) 2015 Annual Meeting, ICA was part of the Urology Care Foundation’s (UCF) Patient Advocacy Hub, a central location for patient advocacy organizations. ICA also held a meet and greet reception, allowing providers, researchers, and ICA staff to network and catch up with each other. ICA made over 60 new healthcare provider contacts and dramatically increased its visibility. We noticed common sentiments among most of the healthcare providers in attendance—they want answers as much as their patients. ICA is encouraged by the increasing interest in and awareness of IC among urologists, which appears to be helping decrease the time to diagnosis and proper treatment. ICA gratefully acknowledges Imprimis Pharmaceuticals, Inc. for its support of the reception.

**ICA LAUNCHES NEW WEBSITE**

ICA revamped its website (ichelp.org) in 2015. Designed to be visually exciting and easily viewed on any mobile device, the new site is intended to help the IC community more easily access the organization’s numerous resources.

Highlights include an updated homepage that’s simpler to navigate, a searchable knowledge base, easy access to the ICA Online Support Community, an interactive map showing search results for healthcare providers and support groups in your area, and effortless access to donor resources.
MAKING THE MOST OF LIMITED RESOURCES

During 2015, ICA continued to serve its role as a good steward of donations by directing as much money as possible to 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 PLLC for the fiscal year ended September 30, 2015. 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, 2015

REVENUE

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<tr>
<th>Source</th>
<th>Amount</th>
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</thead>
<tbody>
<tr>
<td>Federal Grant</td>
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<tr>
<td>Contributions</td>
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<td>Industry Publication Sales</td>
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<td>Other Income</td>
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<td><strong>Total Revenue</strong></td>
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EXPENSES

<table>
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<tr>
<th>Category</th>
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<td>Program services:</td>
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<tr>
<td>CDC Cooperative Agreement</td>
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<tr>
<td>Research</td>
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<td><strong>Total program services</strong></td>
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<td>Supporting services</td>
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<td><strong>Total supporting services</strong></td>
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<tr>
<td><strong>Total expenses</strong></td>
<td><strong>$1,393,420</strong></td>
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</tbody>
</table>

Change in Net Assets from Operations

- ($155,045)

Net Assets, beginning of year

- $866,667

Net Assets, end of year

- $710,862