Fiscal year 2013 was a busy one for the Interstitial Cystitis Association. From a record-setting Patient Education Forum and expanded research opportunities to the launch of online self-help modules for patients and continuing education offerings for healthcare practitioners, 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 2013, ICA worked with members of Congress, the National Institutes of Health, and other federal agencies to ensure that IC remains a part of the conversation as the nation and its policymakers continue to grapple with issues involving pain treatment, management, and research. Our efforts have won federal funding to continue the search for a much-needed diagnostic test that could potentially speed the diagnosis of IC and improve its treatment, while your dollars continue to fund novel approaches to treating IC through the ICA Pilot Research Program. Our Patient Forum brought together patients, healthcare providers, IC researchers, pharmaceutical representatives, and others—including some IC patients who had never been in the same room as others suffering from the condition. We continue to make strides in breaking the crippling isolation that often accompanies IC through our online self-help tool, ICHope, as well as social media and public awareness campaigns that appeared in national media and on more than a thousand billboards across the country.

At the same time, ICA has become a stronger association. We established a board recruitment process which resulted in ten well-qualified applicants interested in serving on ICA’s Board of Directors. Our engagement on social media and public awareness campaigns have resulted in increased attention and use of ICA’s online resources and materials, available at www.ichelp.org. We’re also grateful for our growing family of supporters, who are honored in each issue of ICA Update (visit ICA’s website for a complete list).

The year just passed also marked a transition for the association with my appointment as ICA’s new executive director. I joined ICA in early 2013, following a variety of positions in health and science-based organizations, including my most recent role as director of the Spinal Research Foundation, a patient advocacy organization. I’ve been energized by the opportunity to help improve the quality of life for those suffering with IC.

I, along with the rest of ICA’s staff, board of directors, and the broader IC community, stand prepared to continue the search for better IC treatment—and ultimately, a cure.

Lee Bryan Claassen, CAE
ICA Executive Director
ADVOCACY

The 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. In 2013, we continued to advocate tirelessly to ensure that we do not lose the momentum the IC community has gained.

On the Hill

In January and in June, ICA representatives and IC advocates visited more than 30 Congressional offices to reinforce the message that biomedical research and public health initiatives are essential to help find answers and meet the special needs of the more than 12 million people affected by IC. Advocates asked representatives to consider investing more money in overall biomedical research as well as IC-dedicated research at the National Institutes of Health (NIH), including IC in the scope of the Department of Defense Peer Reviewed Medical Research Program, and funding the Centers for Disease Control and Prevention (CDC) IC Awareness and Education Program.

At NIH

ICA representatives visited leaders of three key institutes at the National Institutes of Health to discuss their portfolios of IC-related research and potential opportunities for collaboration. At NIH’s National Center for Complementary and Alternative Medicine (NCCAM), ICA representatives shared the interest of the IC community in complimentary and alternative medicine (CAM) therapeutic options and shared research from IC patients. Leaders at the National Institute of Neurological Disorders and Stroke (NINDS) urged ICA representatives to remain active participants in the Institute’s Pain Consortium. At the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the conversation focused on the Multidisciplinary Approach to Pelvic Pain (MAPP) Research Network, in whose steering committee ICA participates. Funding for MAPP was approved for a second five-year period, permitting the researchers to continue to focus their efforts on IC and chronic prostatitis. NIDDK also released four new research opportunities for IC researchers.

ICA’s advocacy efforts helped lead to the nomination of Dr. Daniel B. Carr, a member of ICA’s Medical Advisory Board, to the NIH Interagency Pain Research Coordinating Committee. ICA Executive Director Lee Claassen was also selected to serve on the Public Education and Communications Working Group of the same committee. Dr. Carr’s selection into the Committee means that IC will not be left out of the conversation as the committee works to create comprehensive population health strategies for pain prevention, treatment, management, and research, as well as identify critical gaps in basic and clinical research on the symptoms, causes, and treatment of pain.

Other Advocacy

ICA provided oral testimony at a Food and Drug Administration public hearing on chronic opioid therapy, whose role in treating chronic pain conditions like IC has been scrutinized in recent years. ICA urged the FDA to ensure that patients with chronic pain have access to these critical pain medications as the agency moves forward with regulatory work on the serious issues of opioid addiction and misuse. ICA also attended FDA meetings on patient-focused drug development. ICA representatives also met with the Centers for Disease Control, which has a cooperative agreement with ICA.
RESEARCH

The ICA funds small 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.

$750,000 DoD Research Grant to Develop Diagnostic Test for IC
ICA’s advocacy efforts resulted in a $750,000 research grant through the Department of Defense Peer Reviewed Medical Research Program that was awarded to Sonia Planey, PhD, of Commonwealth Medical College in Pennsylvania to develop a potentially definitive diagnostic test for IC. Dr. Planey’s research on the use of antiproliferative factor (APF), a glycopeptide discovered by Dr. Susan Keay, as a diagnostic biomarker for IC, could possibly speed a patient’s time to diagnosis and to earlier, possibly more effective, treatment.

ICA Pilot Research Program Expanded
To increase the amount it dedicates to supporting worthwhile research, ICA revised the eligibility criteria, application process, and increased the award amount of the ICA Pilot Research Program from $10,000 to $25,000 to help spur new investigators and novel projects. To date, more than 100 IC research projects have been funded by the ICA Pilot Research Program.

One project funded in 2013 is The Comorbid Pelvic Pain Modeled by Homo- and Hetero-sensitization of Pelvic Viscera: the Potential Therapeutic Effects of Delta-Mu Opioid Agonist, led by Dr. Matthew Fraser of Duke University Medical Center in Durham, North Carolina. His study will assess how different opioid receptors on pelvic organs affect pain processing, as well as how insulted pelvic organs may sensitize each other. This study will provide insights on the development of IC and other chronic pelvic pain conditions that often coexist with IC, such as irritable bowel syndrome.

Matching Funds to Find a Cure
ICA also worked with an anonymous donor to offer a $50,000 matching-grant program to support IC research. Individual donations of up to $10,000 for the ICA Pilot Research will be matched by the anonymous donor. By the end of fiscal 2013, more than $14,000 had been raised through the program, which has continued to grow in fiscal 2014.

Partnering for Progress
ICA has also established joint research awards with the American Urogynecologic Society and Association of Nurse Practitioners Foundation.

ICA’s ELECTRONIC ENGAGEMENT, BY THE NUMBERS

- 59 email blasts to an average of 28,500 recipients — a 6% increase from the previous year, and with a 15 percent “open rate”—significantly above the industry standard for email campaigns
- 318 Facebook posts, a 192% increase from the previous year, resulted in a 20% increase in new likes, a 74% increase in engaged users, and nearly 1.2 million in total reach, representing a 123% increase in 2013.
- 417,000 individuals visited the ICA website, a 36% increase from the previous year, resulting in 1.9 million page views — a 12% increase from the previous year.

DoD PRMRP Awardee Dr. Sonia Planey with ICA’s Anita Roach.

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Dr. Matthew Fraser

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Patient Education Forum: Knowledge, Hope, and Empowerment

In June, ICA held its 2013 Patient Forum: Empowering IC Patients With Knowledge and Hope in Philadelphia. The free event brought together over 125 patients, caregivers, family members, healthcare providers, IC researchers, pharmaceutical representatives, and others with an interest in IC. All were united by the mission of empowering patients and caregivers with the need-to-know tools for successful management and treatment of the condition.

To broaden and maximize the impact of the event and make it accessible to all, the Patient Forum was streamed live on the day of the event, recorded, and made into a series of webcasts that will be accessible online for one year. The recorded webcasts have been viewed by more than 700 individuals. The average rating for the sessions was 4.2 out of 5, and 96 percent of all participants said they would recommend the Patient Forum to other IC patients and caregivers.

Continued Education for the Healthcare Community

In conjunction with The France Foundation, the American Urogynecologic Society, and Nurse Practitioner Alternatives, ICA launched ICHelpCME.org, an online continuing medical education resource center for healthcare providers on the identification and management of patients with IC. Conquering IC: Identification and Management Strategies, is a free continuing medical education (CME/CE) module focused on the identification and management of IC patients in order to help healthcare professionals more readily recognize the signs and symptoms of IC.

New Resources for IC Patients

ICA launched its free patient self-management module, ICHope. Developed in connection with Pro-Change, ICHope (ichelp.org/ichope) is the first-of-its-kind computer-tailored intervention for patients experiencing IC pain. Focused on self-management, ICHope provides patients with the tools they need to regain control of their lives, including finding a committed healthcare provider, identifying self-care strategies, and using healthy methods to stay hopeful and empowered.

ICA also launched the online ICA Healthcare Provider Registry, which includes more than 1,000 healthcare providers, including physicians, nurse practitioners, physical therapists, dietitians, and counselors. Available at www.ichelp.org/HealthcareProviderRegistry, the registry is free for patients and clinicians.

ICA’s free webinar, IC’s Role in CAPPS (Complex Abdominal-Pelvic Pain Syndrome), drew 275 live views and 668 recorded views through the year. ICA also continues to produce and distribute ICA Update, the association’s signature publication providing credible and relevant resources and information to the IC community, and exchanged content with other organizations, including the Sjögren’s Foundation.

Broadening Visibility

ICA launched a national billboard campaign in which more than 1,000 billboards sharing information about IC were placed in more than 40 markets across the country, including 100 Spanish-language billboards in Los Angeles. Providing the public with information about IC and directing them to get the facts at ICA’s website, ichelp.org, the campaign was supported by social media and resulted in a 6.3 percent increase in total visits to ichelp.org, a 4.5 percent increase in new visitors, and increases in visit length and depth. Facebook followers rose by 228 percent, iTunes downloads increased 676 percent, and views of ICA’s YouTube videos increased by 966 percent.

ICA also ran IC awareness advertising in USA Today’s Charity Spotlight for six months of the year and disseminated information about IC by participating in a range of meetings, including the New York State Pain Society and the US Pain Foundation’s Patient Summit, the Alliance for Pelvic Pain’s Patient Retreat, the American Urologic Association Annual Meeting, the International Pelvic Pain Society Annual Meeting, and the American Urogynecologic Society Annual Meeting.

The 2013 Patient Forum, ICHelpCME.org, ICHope, the ICA Healthcare Provider Registry, and the national billboard campaign were supported by the Cooperative Agreement 5U58DP002936-03 from the Centers for Disease Control and Prevention.
During 2013, ICA continued to maintain the call to be a good steward of donations by directing as much money as possible to the programs and services vital in the support of education and research for IC. The following is a summary of the financial statements incorporated in the annual audit report issued by Rogers & Company PLLC for the year ended September 30, 2013. The complete financial statements and notes are available to view in the About Us section of ICA’s website, www.ichelp.org.

Making the most of **LIMITED DOLLARS**

to **FIGHT IC**

**STATEMENT OF ACTIVITIES**
For the Year Ended September 30, 2013

**REVENUE:**

- Federal Grant: $563,918
- Contributions: $543,831
- In-Kind Contributions: $300,000
- Publication Sales: $12,633
- **Total Revenue:** $1,419,393

**EXPENSES:**

- Program Services:
  - CDC Cooperative Agreement: $485,130
  - Research: $80,060
  - Advocacy: $157,012
  - Education: $563,929
  - **Total Program Services:** $1,286,131

- Supporting Services:
  - Administration: $100,913
  - Fundraising: $77,216
  - **Total Supporting Services:** $178,219

- **Total Expenses:** $1,464,260

- Change in Net Assets from Operations: ($44,876)
- Investment Loss: ($4,802)
- **Change in Net Assets:** ($49,669)
- Net Assets, beginning of year: $870,692
- Net Assets, end of year: $821,023

**Interstitial Cystitis Association**
1760 Old Meadow Road, Suite 500  |  McLean, VA  22102  |  www.ichelp.org