As the Interstitial Cystitis Association celebrated its 30th anniversary in 2014, the association continued to focus on the same three missions that have driven it since its founding—advocacy, research, and education. From the creation of an online support community to growing collaboration with other organizations focused on overlapping chronic pain conditions, 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.

FROM THE EXECUTIVE DIRECTOR

Three decades ago, ICA was founded after medical resident Vicki Ratner, MD, couldn’t find an explanation or treatment for her persistent and painful symptoms. Thousands of people suffering in silence across the country heeded the call, helping create a patient advocacy group that has led IC to become recognized, researched, funded, and much better understood by the medical community.

In 2014, ICA continued to build on the legacy of the past three decades, pursuing a three-pronged mission to educate, advocate, and ensure that research continues to be focused on better understanding IC. We launched an online support community to better serve IC patients, as well as their families and caregivers. We continued our advocacy for IC research on Capitol Hill and at the National Institutes of Health, and strengthened our connections with organizations focused on overlapping chronic pain conditions. And we launched an unprecedented effort to educate the medical community and gauge their understanding of IC, with unprecedented results. We are on the cusp of ensuring that IC is no longer a condition that will be misdiagnosed or ignored by primary care providers, something that would have been unthinkable three decades ago.

Our ongoing efforts to strengthen ICA have also borne fruit with the growth of our Board of Directors and Medical Advisory Board, along with a restructuring of our membership program to provide a greater range of benefits and more ways to support IC research and advocacy.

As we celebrate three decades of tireless advocacy for the more than 12 million people suffering from IC, we have the opportunity to look at how far we’ve come—and the hard work ahead to ensure we continue the search for better IC treatments, understanding of the condition, and ultimately, a cure. As we move into the next three decades, I, along with the rest of ICA’s staff, its Board of Directors, and the broader IC community thank you for your continued support in the years to come.

Lee Bryan Claassen, CAE
ICA Executive Director

New Ways to Support ICA

ICA has restructured its membership program to provide more 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.
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 2014, ICA worked with a growing number of stakeholders to ensure we maintain momentum for the more than 12 million Americans affected by IC.

On the Hill
During Capitol Hill visits in 2014, ICA representatives visited 30 Congressional offices representing nine states to educate lawmakers about the needs of IC patients everywhere. ICA continues advocating to ensure that IC research and education is supported in the federal FY15 budget by requesting that lawmakers consider:

- 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.
- Maintaining the Centers for Disease Control and Prevention (CDC) IC Education and Awareness Program.
- Including 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.

Focusing on Chronic Pain
In March 2014, ICA joined 16 organizations to form the Consumer Pain Advocacy Task Force (CPATF) to unite around one goal—to work collectively to promote, support, and monitor the implementation of the National Pain Strategy (NPS). The following beliefs guide CPATF’s collective work:

- Chronic pain is a real and complex disease that may exist by itself or be linked with other medical conditions.
- Chronic pain is an unrecognized and under resourced public health crisis with devastating personal and economic impact.
- Effective pain care requires access to a wide range of treatment options.
- Allowing people to suffer with unmanaged pain is immoral and unethical.

ICA also became a founding member of the National Coalition of Chronic Pain Providers and Professionals, a network of health providers, professionals, and organizations working on behalf of individuals with chronic pain, their families, and their caregivers.

At NIH
As the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) research network enters its second five-year phase, ICA participated in steering committee meetings sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health (NIH). ICA provided the patient perspective for the protocols that will guide MAPP’s second phase, which continues earlier work to study underlying causes of IC/painful bladder syndrome and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) and begins to explore potential therapies.

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 2014:

- In June, ICA participated in the Urology Care Foundation Overactive Bladder Roundtable to explore collaborative actions to help meet the gaps in pelvic health advocacy.
- ICA Executive Director Lee Claassen shared the podium with ICA Founder and President Emeritus Dr. Vicki Ratner at ESSIC, the International Society for the Study of Bladder Pain Syndrome (BPS). Hosted for the first time in the United States, ESSIC’s annual meeting provided an international forum to exchange research results, experiences, and ideas on BPS/IC.
- ICA’s Claassen served on a panel of patient advocates during the TMJ Association scientific meeting in September. The meeting focused on the epigenetic and genetic factors in temporomandibular disorders (TMD) and their overlapping pain conditions, one of which is IC. Members of the panel advocated for continued research in identifying the causes, potential connections, and treatments for overlapping chronic pain conditions.

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.
ICA Pilot Research Program

In 2014, ICA awarded three ICA Pilot Research Grants to talented researchers seeking to improve our understanding of IC, with the greater hope of creating a world where IC is a thing of the past. To date, more than 100 IC research projects have been funded through the support of the ICA Pilot Research Program.

Larissa Bresler, MD, of Loyola University, received a grant for her research on Acupuncture for FemaleInterstitial Cystitis/Painful Bladder Syndrome. Dr. Bresler and her team are attempting to determine the safety and tolerability of acupuncture in women with IC/PBS, as well as whether acupuncture is effective in reducing pain in women with IC/PBS. The impact and potential benefits of identifying new nonpharmacologic treatments in women with IC/PBS will be critical to reduce disease severity and improve quality of life across female IC/PBS patients and all chronic pelvic pain subtypes.

Jayoung Kim, PhD, of Cedars Sinai Medical Center, received a grant for Interstitial Cystitis-Associated Microbiome and Proteome as Diagnostic Markers. Dr. Kim and her team are trying to identify and validate IC-associated urinary diagnostic biomarkers. The study has the potential for significant clinical impact because the results may lead to clinical methods to increase diagnostic accuracy and an improved understanding of the molecular basis of IC and its relationship to urologic conditions with overlapping symptoms.

Stephen Walker, PhD, of Wake Forest University Health Sciences, received a grant for Correlation of Gene Expression with Bladder Capacity in Interstitial Cystitis. Dr. Walker and his team are determining whether bladder capacity is a key delineating factor that differentiates IC subtypes.

ICA/AUGS Research Grant

A research grant jointly funded by ICA and the American Urogynecologic Society (AUGS) was awarded to Judy M. Choi, MD, of the University of California, Los Angeles. Her study, Chronic Stress Affects the Micturition Pathway via the Peripheral Corticotropin-Releasing Factor (CRF) Pathway, is identifying the connection between chronic stress and the development of IC/PBS.

ICA Strengthens Governance

ICA continued to draw increased support and leadership in 2014, adding three new members to its Board of Directors and one new member to its Medical Advisory Board.

New members of the Board of Directors are:

Jann Keenan, EdS, is a health literacy specialist and active community volunteer. Since 1995, she has served as president of the Keenan Group Inc., a social marketing and multimedia design firm. Keenan is also a strategic partner with the Institute for Healthcare Advancement. An IC patient, Keenan and her family call Maryland home.

Rick Lufkin is a serial entrepreneur in the life sciences specializing in early-stage pharmaceutical, biotechnology, and medical device companies. He currently serves as CFO and director of a firm exploring and advancing real-time protein identification. As president of a specialty pharmaceutical company, he was involved with the early drug approval process for Elmiron, working closely with IC patients, physicians, and regulatory authorities. He and his wife live in New Jersey.

Joy H. Selak, PhD, became too ill to work after being diagnosed with IC and other autoimmune and neurological conditions at 40. She found effective, supportive care and asked her physician to co-author a book with her about their shared experience. You Don’t LOOK Sick! Living Well with Invisible Chronic Illness is now in its second edition. After 20 years of illness, she is now working for an arts education non-profit and is committed to helping others build meaningful lives with long-term illness.

Robert Echenberg, MD, joined the ICA Medical Advisory Board. Dr. Echenberg has decades of experience assessing, diagnosing, and treating chronic pelvic, genital, and sexual pain disorders.

MAPP Enters Phase 2

As the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) research network begins its second five-year phase, ICA Board Member and Medical Advisory Board Liaison Robert Moldwin, MD, was selected to serve on the network’s executive committee.
**Bringing Support Online**
ICA launched a new Online Support Community for patients, family members, friends, and healthcare professionals. The secure, peer-to-peer, moderated forum allows IC patients and their supporters to discuss topics like “Living with IC,” “IC Diet,” and “Management of IC Pain.”

Join the conversation and connect with hundreds of other people experiencing similar symptoms, situations, and emotions at www.ichelp.org/OnlineSupportCommunity.

**Virtual Education**
To ensure that opportunities for IC education reach as large an audience as possible, ICA hosted several hour-long Facebook chats in 2014, including a discussion on diet and IC (see a transcript at www.ichelp.org/FBChatDiet) and a chat on intimacy and IC (see www.ichelp.org/FBChatIntimacy for a transcript).

**ICHope**
To foster awareness of ICA’s free patient self-management module, ICHope, Dr. Mary Ruth Valicki, a physical therapist, IC patient, and author of Healing Through Chronic Pain, a Physical Therapist’s Personal Journey of Body, Mind, Spirit Transformation, answered questions and shared her personal experience with ICHope during a free webinar, available at www.ichelp.org/VirtualPatientEducation.

**Improving Clinician Understanding**
To increase awareness and up-to-date information about IC among the broader medical community, ICA distributed a special issue of ICA Update to more than 100,000 healthcare providers, including federal health agencies, community health nurses, college health centers, family physicians, internists, emergency physicians, nurse practitioners, and physician assistants. Findings from a follow-up survey of clinicians, most of whom were family physicians working in private practice, included:

- 96 percent had heard of IC before reading the special issue.
- 63 percent had treated patients diagnosed with IC. However, only 13 percent had diagnosed these patients with IC.
- 50 percent indicated they were very confident they would recognize the symptoms of IC after reading the special issue.
- 67 percent said they were very confident they could refer an IC patient to the appropriate specialist for treatment in a timely manner.
- All participants indicated they planned to refer patients to ICA’s website, ichelp.org, for the latest information on IC.

**AUA Clinical Guideline Changes**
In October 2014, ICA informed the IC community that the American Urological Association Clinical Guideline for the Diagnosis and Treatment of IC had been updated to be current with newly published research. Key changes include moving Botox from a fifth-line to a fourth-line treatment.

**Broadening Visibility**
ICA continued efforts to increase awareness of IC among the general public. Continuing a billboard campaign that began in 2013, ICA posted an additional 618 billboards in 17 markets across the country between January 1 and April 15, 2014, providing the public with knowledge of IC and directing them to get the facts at www.ichelp.org. Recent ICA media coverage that has increased public awareness and knowledge about IC included:

- An October 14, 2013 segment of The Doctors.
- A March 29, 2014 supplement to the Los Angeles Times.
- The April 2014 issue of Prevention.
- The May 2014 issue of Health.

ICA also participated in the Urology Care Foundation Patient Advocacy Hub during the American Urological Association’s 2014 annual meeting, with more than 17,000 attendees from around the world. In addition, ICA disseminated information and promoted its resources and services during the following meetings:

- International Pelvic Pain Society (IPPS) Annual Scientific Meeting, October 2013
- American Urogynecologic Society (AUGS) 34th Annual Scientific Meeting, October 2013
- Society of Urodynamics, Female Pelvic Medicine & Urogenital Reconstruction (SUFU) 2014 Winter Meeting, February 2014
- Alliance for Pelvic Pain Retreat, June 2014
- Joint meeting of the American Urogynecologic Society and International Urogynecologic Association, July 2014
Electronic Engagement, By the Numbers

ICA’s use of online and social media to spread public awareness and reach out to IC patients continued to grow in 2014:

- **98 email blasts** to an average of 29,703 recipients, a 4% increase from the previous year, with a 16% average open rate
- **387 Facebook posts**, a 22% increase from the previous year, resulting in a 34% increase in new likes, a 195% increase in engagement, and nearly 3.9 million in total reach—a 261% increase.
- **654,111 individuals visited the ICA website**, a 57% increase from the previous year, resulting in 2.6 million page views—a 37% increase.

Making the Most of Limited Resources

*During 2014, 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, 2014. 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, 2014

**REVENUE**

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<th>Source</th>
<th>Amount</th>
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<tr>
<td>Federal Grant</td>
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<td>Contributions</td>
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<td>Industry Publication Sales</td>
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<td>In-Kind Contributions</td>
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<td>Publication Sales</td>
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<td><strong>Total Revenue</strong></td>
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**EXPENSES**

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<th>Category</th>
<th>Amount</th>
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<td>Program services:</td>
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<td>CDC Cooperative Agreement</td>
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<td>Research</td>
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<td>Advocacy</td>
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<td>Education</td>
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<td><strong>Total program services</strong></td>
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<tr>
<td>Supporting services:</td>
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<td>General and administrative</td>
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<tr>
<td>Fundraising</td>
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<tr>
<td><strong>Total supporting services</strong></td>
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**Total expenses**  

$ 1,374,432

**Change in Net Assets from Operations**  

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<th>Type</th>
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<td><strong>Change in Net Assets</strong></td>
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<td>Net Assets, beginning of year</td>
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<tr>
<td>Net Assets, end of year</td>
<td>$ 866,667</td>
</tr>
</tbody>
</table>

ICA's office relocated in Fall 2014 to  
7918 Jones Branch Drive, Suite 300, McLean, VA 22102.  
Be sure to update your address books!