ICA Annual Report

Fiscal Year Ending September 30, 2009

Mission & Vision

Advocacy

Research

Education

Financial Stewardship

Thanks

Mission & Vision

**MISSION**
The Interstitial Cystitis Association provides advocacy, research funding, and education to ensure early diagnosis and optimal care with dignity for people affected by IC.

**VISION**
Conquering IC. Changing Lives.
Message from the Executive Director

In the spring of 2009, the ICA Board of Directors conducted a strategic planning meeting that included a discussion of what is occurring in the world of IC. The board concluded that:

- Knowledge about IC and its treatment is far more widespread and sophisticated among physicians and patients than it was when the ICA was founded more than 25 years ago.
- The ICA has every right to be proud of its successes in achieving recognition for IC and its effects on patients’ lives, and for advocating for funds to research causes and possible treatments.
- Many challenges remain. No cure has been found, and no treatment, alone or in combination, is universally effective.
- Too many caregivers and patients lack accurate information about IC. Too many patients are subjected to ineffective treatments and are improperly diagnosed. Too many patients suffer too much pain.

The ICA Board also discussed where to direct future energies. Some of the programs undertaken over the years are no longer the most effective use of resources. Sources of funding have changed. One unequivocal outcome of the meeting was a revitalized commitment to making a difference in the lives of IC patients, caregivers, researchers, and healthcare providers. We invite you to join us in this battle to overcome IC.

Barbara Gordon, RD
At the core of our mission is an effort to help healthcare providers, payers, researchers, legislators, and others understand the continued need to learn more about IC.

Ongoing advocacy efforts urge leaders to take impactful actions to find the answers.

The ICA Gets the Voices of the IC Patients Heard
On the Ground in Washington, the ICA Gets the Voices of IC Patients Heard

**Passage of the National Pain Care Policy Act**

Joining forces with more than 100 organizations, thousands of IC patients and other committed individuals, the ICA helped get the 2009 National Pain Care Policy Act Update signed. This legislation requires the NIH to expand research on causes and treatments for pain; provides comprehensive pain care education and training for healthcare providers; creates a national public awareness campaign on pain management; and authorizes an Institute of Medicine conference on pain management.

**Educating Congress about IC**

In a series of meetings with congressional staffers, ICA staff and the Board of Directors emphasized the importance of government-funded IC research and awareness efforts. Meetings included talks with legislative aids for Senator Henry Reid (NV) and Representatives Rosa DeLauro (CT) and Nita Lowey (NY). Educational materials that highlighted the need for continued IC-dedicated research and awareness efforts were shared and discussed.
In the Chambers of Congress,  
the ICA Gets the Voices of IC Patients Heard

U.S. Senate committee report highlights IC

ICA efforts led to a recommendation by the US Senate Committee on Appropriations for expanded research dedicated solely to IC be conducted through the National Institutes of Health (NIH). The Congressional report cites the significant drop in overall funding for IC in spite of recent epidemiology research findings that demonstrate increased prevalence of the condition to about 4 million Americans, nearly fourfold the original estimates.

Awareness about IC has increased significantly during the last several years; however given the significant increase in the prevalence of IC in the US, the Senate Committee on Appropriations recommended continued funding for dedicated IC awareness activities.

Congress tells DOD to sponsor IC research

At the urging of the ICA, the US Senate Committee on Appropriations for the Department of Defense (DoD) named IC as one of the selected areas of study for fiscal year ending September 30, 2010. The DoD Peer Reviewed Medical Research Program dedicates $50,000,000 for projects of clear scientific merit and direct relevance to military health.
In the Debate about Healthcare Reform, the ICA Gets the Voice of IC Patients Heard

Dear President Obama
The ICA joined forces with 48 other national patient groups calling on President Obama and members of Congress to enact healthcare reform legislation that guarantees effective and affordable health and long-term care coverage for all Americans.

Eliminate lifetime caps
The ICA joined a coalition of patient and scientific groups speaking out about the need to immediately eliminate lifetime caps for all health insurance plans.
**At the Table for Clinical Care Discussions, the ICA Gets the Voices of IC Patients Heard**

**IC treatment guidelines**

As a member of the American Urological Association (AUA) IC Treatment Guidelines Committee, the ICA participated in vetting evidence-based literature and offering the patient perspective on treatment needs. At numerous meetings during the past year, ICA Executive Director Barbara Gordon educated physicians about the special needs of IC patients.

**Coverage for diet counseling**

Executive Director Gordon attended a congressional briefing about the importance of diet in the treatment and management of chronic disease.

Researchers presented the findings of a survey co-sponsored by the University of Tennessee and the American Dietetic Association (ADA) that found that the majority of doctors (83%) noted that lack of direct reimbursement is the main reason they do not offer nutrition counseling to patients with chronic diseases. Most physicians (88%) also noted that medical doctors do not have enough time to talk with patients about diet.
Empowering Patients,
the ICA Gets the Voices of IC Patients Heard

“ICA means a great deal to me. Having IC for 30 years I feel I have grown with you. The information provided is valuable—30 years ago no one (had) heard of IC, now some have their ears open. The information/research received from ICA gets passed to all my doctors.”

Responding to public inquiries
ICA staff answered thousands of calls and emails from patients, healthcare providers, researchers and the public.

Linking patients and providers
We linked patients with other patients, patients with healthcare providers, and healthcare providers with other healthcare providers for better networking, education and treatment.

Social Security disability
Our team also helped patients navigate the social security and private disability system.
The research focus of the ICA sets the organization apart from other groups.

Our reach is much more than monitoring the latest findings, translating results into plain language, and helping move discoveries from bench to bedside. We fund research grants and conduct studies on patient trends.

The ICA Makes Research Happen
As a “Beacon” in the Lab, the ICA Makes Research Happen

Results of two ICA pilot research programs hold hope of diagnostic blood test

A group of scientists at The Ohio State University, under the leadership of Tony Buffington, DVM, MS, PhD, discovered biomarkers with the potential to identify IC. The team found increased levels of tryptophan and its metabolite kynurenine in people with IC. Follow-up studies are also indicating that IC may be coming from the central nervous system.

During the past year, a urine test to diagnose IC was also developed by Sonia L. Planey, PhD, and her team at The Commonwealth Medical College. The patent-pending test detects the presence of antiproliferative factor (APF), the urinary marker discovered by Susan Keay MD, PhD, and her team at the University of Maryland through research funded by the ICA Pilot Program and the Fishbein Foundation.
A single observation and careful study

Thomas Chelimsky, MD, a neurologist with Case Western University in Cleveland, Ohio, noticed that many of his patients with a variety of autonomic disorders also had IC, and that some of them also had family members with autonomic disorders and IC.

With a small grant from the Fishbein Foundation, Dr. Chelimsky investigated the hypothesis that IC patients suffer from overlapping conditions such as irritable bowel syndrome, fibromyalgia, complex regional pain syndrome, migraine headache and others.

Dr. Chelimsky found that the patients and their family members might be expressing these syndromes because of undiscovered genetic or environmental factors, or both. He postulates that if IC occurs later in the progression of autonomic disorders, this would account for the large number of associated disorders seen with IC. With these initial results in hand, Dr. Chelimsky applied and was awarded a grant through the NIH to study this phenomenon more extensively.
The ICA continued to urge NIH to sponsor more IC-dedicated research

To thank NIDDK for their research efforts and encourage more dedicated IC research, ICA Board member Dr. Robert Evans and Executive Director Barbara Gordon met with NIDDK leadership.

During the meeting, the research team of the NIH-funded RAND Interstitial Cystitis Epidemiology (RICE) study also briefed ICA leaders on the preliminary findings of this national study, notably a marked increased in the prevalence of IC among women 18 years of age and older in the US. Given a significant increase in the prevalence, the ICA asked that NIDDK step up research efforts and award stimulus funds to IC projects.

In March 2009, the RICE research team released insights from interviews with 100,000 households in the US. The big news was a significantly greater prevalence among women 18 years and older in the US with symptoms of IC. We now know that 3 to 8 million women may have IC.

The ICA and the Prostatitis Foundation met with key NIDDK leaders to urge them to expand the RAND study to look at the prevalence of IC in men and of chronic prostatitis/chronic pelvic pain syndrome. The conversation was followed up with a letter to NIDDK Director Griffin Rodgers encouraging more focus on IC and CP/CPPS epidemiological, basic science, and biomarker research.
ICA efforts also ensured continuation of large-scale, national studies

Multidisciplinary Approach to Pelvic Pain Research Network: Researchers from this multi-site, multi-million dollar study are investigating:

- Epidemiology (how and why people develop IC)
- Phenotyping of symptoms (subgroups)
- Neuroimaging (brain function)
- Biomarkers, and organ cross-talk pain pathways

Researchers participating in the network have developed a clinical protocol to standardize future collection of data from the six participating research sites. ICA staff and medical advisory board members attended steering committee meetings, advising the research team on special considerations for IC patients participating in clinical studies.
On the Web, the ICA Makes Research Happen

Clinical trial recruitment helped researchers learn more about IC

During the past year, we reached out to our robust IC community, informing patients of investigatory treatments and helping to recruit patients for clinical trials.

Online patient surveys highlighted important aspects of living with IC

The ICA conducted monthly surveys of the patient community. These surveys gave us insights into the patient experience with diagnosis, self care strategies, healthcare provider interactions, pain management protocols and more, which we then shared with the community.

During the past year, ICA surveys discovered that nearly one-quarter of IC patients are diagnosed within 6 months, nearly half (39%) within 1 year of symptoms developing.
Inter-what? The ICA continued to work with the Centers for Disease Control and Prevention to increase understanding about IC among healthcare providers and the public. Harnessing a variety of outreach and public relations tools, we cast a national promotional net.

The ICA Raises Awareness
In the Trade and Mainstream Media, the ICA Raises Awareness

Awareness increased during the year
Stories in the popular press were covered in *Self* and *O* (The Oprah Magazine). There was also an emergence of more IC-dedicated blogs and websites, emphasizing the increased need for the ICA website as a trusted voice of sound information.

The *ICA Update* continued to offer unique reporting
The covers of the *ICA Update* featured artwork by IC patients. Additionally, a special issue featured contributions about overlapping conditions from sister nonprofit organizations.
In Cyberspace, the ICA Raises Awareness

A revamped website translated to a wider virtual reach
The ICA website was revamped and updated during the past year, for easier site navigation. Practical information such as living with IC on a budget, patient assistance programs, and finding restrooms on the go was also added. Each month our online news digest, Café ICA, publicized the latest in research, treatment options and coping strategies.

A live webcast drew the interest internationally
The A to Z on IC patient forum, held in Atlanta, Georgia on August 23, 2009, combined an in-person forum with a live streaming interactive webcast—450 people online from 43 states and 9 countries joined the 100 patients gathered in an Atlanta hotel. Speakers included:

- Jeffrey Proctor, MD who presented an overview of IC
- Susan Bilheimer, IC patient and author, shared intimacy tips
- Anna Kelly, MD, who demonstrated how acupuncture can be used to treat pain
Breaking news was broadcast via same-day email blasts
More than 40,000 users logged on to the ICA website on a daily basis to read the summaries of IC related sessions of the American Urological Association annual meeting. The ICA was a key source for the breaking news that some 3 to 6 percent of American women—3 to 8 million—have IC symptoms. That surprising new estimate was the biggest IC story at 2009’s annual meeting of the American Urological Association (AUA), held in Chicago in April. Much bigger than most previous estimates, the numbers should bring more recognition, research effort, and better treatments to IC.

Representing IC patients at international medical meetings
At the IFFGD International Symposium, Executive Director Barbara Gordon participated in a hands-on workshop for creating more effective physician-patient communication. The goal of the workshop was to help physicians learn more effective strategies for communicating with chronic pain patients.
The ICA contributed to a textbook for healthcare providers

With the goal of continuing to educate the healthcare community about IC, Executive Director Barbara Gordon served as a consultant in the development of a textbook entitled *Incontinence, 4th Edition*, edited by Paul Abrams, MD, Linda Cardozo, MD, Saad Khoury, MD, and Alan Wein, MD (co-chair of the ICA Medical Advisory Board).

Developed by an international, multidisciplinary faculty of more than 200 experts, the book includes a short chapter on IC and refers healthcare providers to the ICA for more information. Dianne Newman, RN, ICA Medical Advisory Board member, chaired the patient education committee.
On the Floor of Exhibit Halls, the ICA Raises Awareness

- **American Dietetic Association** annual meeting: Presentations included a posted session about IC. The ICA educated dietitians about the special dietary needs of people with IC.

- **American Academy of Pain Management** clinical conference: Information packets were distributed and healthcare providers were asked to participate in the healthcare provider registry. Highlights of educational scientific sessions were presented in the *ICA Update*.

- **American College of Obstetrics and Gynecology** annual meeting: With the help of an independent social science research company, the ICA conducted intercept interviews with attendees regarding the interdisciplinary IC healthcare team. Results were incorporated into educational information about working with a team of specialists to ensure optimal care.

- **Society of Urologic Nurses and Associates** annual conference: The ICA disseminated information in the exhibit hall and educated more than one hundred healthcare professionals about IC, treatment options, and the latest research.

- **National Association of Nurse Practitioners in Women's Health** annual meeting: More and more nurse practitioners are becoming primary providers for people with chronic conditions like IC. At this meeting, the ICA stressed that it is vitally important they have the most up-to-date information and treatment options for IC.

- **American College of Nurse Practitioners** conference: The ICA's goal for these educational efforts with nurse practitioners is to increase awareness, speed time to diagnosis, and educate about effective treatment options.
The ICA truly appreciates each donation, grant and sponsorship contribution. During the past year, We took a serious look at how we do business. The outcome was the introduction of new management approaches which will permit more efficient use of funds, translating to a higher percentage of funds to go directly to our mission.

The ICA is a Financial Steward
By Spending Donations Wisely, the ICA Makes a Real Difference

- Programs and Services: $1,238,410
- Fundraising: $120,362
- Administration: $156,933

By Spending Donations Wisely, the ICA Makes a Real Difference
Patients, healthcare providers, researchers, industry partners, government leaders, and many others are the reason the ICA exists. The contributions and gifts reflect the desire of the IC community to continue to sustain a nonprofit organization working toward optimal care and ultimately a cure.

We thank those who make this important work happen.
ICA Board of Directors

Comprised of people with IC, family members of those with IC, physicians, and professionals, the ICA Board of Directors guide organizational direction, spur interest in programs and services, and provide fiduciary oversight. This group of volunteers dedicates their time, expertise, and enthusiasm to ensuring ICA mission fulfillment.

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F. Neal Thompson, CFP, Founder and President, Financial Services Consultants
Paula Whelan, ICA Patient Advocate
Barbara Zarnikow, Elementary School Teacher and ICA Patient Advocate
ICA Medical Advisory Board

The ICA Medical Advisory Board provides clinical expertise—reviewing research grant materials, interpreting guidelines and protocols, and providing a link to the medical community.

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- John W. Warren, MD, University of MD School of Medicine
- Ursula Wesselmann, MD, PhD, University of Alabama
- Kristene E. Whitmore, MD, Drexel University College of Medicine

Special Consultant: Monica Liebert, PhD, University of Michigan

NIDDK Liaison: Chris Mullins, PhD, Director, Basic Cell Biology Program
ICA Staff & Patient Advocates

A team of dedicated staff members advocate on behalf of the IC community, work to expand IC research funding, and help patients, healthcare providers, and the public better understand the challenges of living with IC. Our team includes both full-time and part-time staff, some of whom are IC patients.

**Current ICA Staff**
- Penny Allen
- Gary Fackenthall
- Barbara Gordon
- Debi Kerr
- Nicki Mehall
- Linda Salin
- Marilynn Schreibstein
- Deanne Zwerk

**Patient Advocates**
- Paula Berkowitz
- Julie Beyer
- Ilianna Brockman
- Bonnie Hana
- Norma Kellen
- Theresa McCoy
- Kevin Noa
- Ken Paylor
- Susan Presberg-Green
- Jareena Somer
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