INTERSTITIAL CYSTITIS ASSOCIATION ANNUAL REPORT

BEYOND THE BLADDER: MOVING TOWARD BETTER UNDERSTANDING

Annual Report for the Fiscal Year Ending September 30, 2008
The Interstitial Cystitis Association (ICA) is committed to finding more effective treatments and ultimately a cure for interstitial cystitis (IC). Interstitial cystitis is an often painful, chronic bladder condition that severely affects the quality of life for millions of individuals in the United States and throughout the world.

The ICA is an organization of many. Dedicated staff members, compassionate volunteers and generous financial contributors all play a role to:

• Promote and fund research
• Advocate for IC patients, healthcare providers, and researchers
• Educate the medical community and public
• Offer support for IC patients and their families
BEYOND THE BLADDER: MOVING TOWARD BETTER UNDERSTANDING

In an online survey conducted through the ICA’s website in June 2008, more than 85% of participating IC patients reported that they had been diagnosed with and treated for at least one other known related condition – such as irritable bowel syndrome (IBS), fibromyalgia, or chronic fatigue syndrome (CFS) – in addition to IC. One puzzling factor to emerge from this data is that half of the patients surveyed reported that their IC symptoms came first, while the other half reported the related condition symptoms preceded their IC symptoms. Clearly, there is much we still have to learn about root causes and overlapping conditions.

LINKING IC WITH OTHER CHRONIC CONDITIONS

Research first conducted in 1997 by Dr. Madhu Alagiri et al. was in the news again this past year. Alagiri and his research team observed what many IC patients – along with their healthcare providers, friends and loved ones – recognized long before: there is something going on that extends beyond the bladder. The co-occurrence of other chronic diseases with IC and with one another, are at measurably higher rates than in the general population.

During the past fiscal year, new research findings regarding overlapping conditions have echoed Alagiri’s observations. For example:

- A collective study based out of the University of Maryland found 11 chronic conditions to be more common in IC patients than in the healthy controls: allergy, depression, migraine, irritable bowel syndrome, panic disorder, endometriosis, asthma, fibromyalgia, chronic widespread pain (CWP), chronic fatigue syndrome, vulvodynia, and sicca (Sjögren’s) syndrome. ¹

- A University of Michigan Medical Center team presented a comorbidities research study which found 23 chronic conditions to be more common in people with IC, including a host of urinary tract ailments, fibromyalgia, IBS, back pain, anxiety, depression, gastritis and other GI tract problems. ²

- Researchers at the William Beaumont Hospital in Royal Oak, Michigan report that the correlation between IC and vulvodynia has been underestimated. Their initial findings indicate that 25% of women with IC also suffer from vulvodynia. ³

CREATING AWARENESS OF THE CONNECTION

IC awareness and education messages now routinely include information about how interstitial cystitis can be related to a host of other chronic conditions. In the past year, the ICA forged relationships with other independent nonprofit organizations and formed the Overlapping Conditions Alliance to collaboratively leverage the strength of a united message. Because of strong ICA advocacy, the National Institutes of Health (NIH) agreed to fund a multi-year study to further understand the possible relationships between IC and several related conditions.

This extraordinarily significant paradigm shift necessitates a very different, innovative approach. We need to begin to think beyond the bladder.


² J Urol. 2008 Jun;179(6):2222-5. Epub 2008 Apr 18. Case-control study of medical comorbidities in women with interstitial cystitis. Clemens JQ, Meenan RT, O’Keeffe Rosetti MC, Kimes TA, Calhoun EA. Department of Urology, University of Michigan Medical Center, Ann Arbor, Michigan 48109, USA. qclemens@umich.edu

OUR MISSION

Promote and fund research ................................................................. 1
• Advance knowledge about overlapping conditions .................. 1
• Fund IC seed research ................................................................. 1-2
• Promote the latest research findings ........................................ 2-3
• Track changing IC statistics ....................................................... 3

Advocate for IC patients, healthcare providers, and researchers .... 4
• Provide a voice for the IC healthcare community ..................... 4
• Advance public policy ................................................................. 4-5
• Crusade for the IC patients who are in chronic pain ................. 6-8

Educate the medical community and public .............................. 9
• Expand understanding within the healthcare community .......... 9-10
• Educate future physicians .......................................................... 10
• Raise awareness of the general public .................................... 11-14

Offer support for IC patients and their families ......................... 15
• Respond to public inquiries ........................................................ 15
• Sponsor patient forms ................................................................. 15
• Provide 24/7 access to health information ............................... 15

ENSURE SOUND FISCAL PRACTICES ........................................ 16
Financial Highlights of Fiscal Year
Ending September 30, 2008 .......................................................... 16-17
**ADVANCE KNOWLEDGE ABOUT OVERLAPPING CONDITIONS**

The ICA has an ongoing commitment to research advocacy, funding, and promotion. Therefore, it should not come as a surprise that many of the landmark IC research achievements across the last 25 years – including the connection of IC with other chronic conditions – are a direct result of ICA efforts. We sustained our dedication to these areas throughout fiscal year 2008.

During the past year, the ICA continued work to ensure that the Multidisciplinary Approach to Pelvic Pain (MAPP) Research Network, sponsored by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), became a reality. This five year, federally-funded MAPP initiative dedicates more than $37,500,000 to uncovering the connection between IC and overlapping conditions. In a major shift from the past, the research employs a multidisciplinary, highly collaborative, multi-site foundation to conduct basic science, translational and clinical research on chronic pelvic conditions – interstitial cystitis/painful bladder syndrome (IC/PBS) and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS), and their potential links with related conditions – from an expanded systemic point of view. Through its key position on the MAPP steering committee, the ICA will continue to play an integral role in the development of this groundbreaking initiative.

**FUND IC SEED RESEARCH**

The ICA Pilot Research Program remains the first and only interstitial cystitis research program funded by a non-profit, patient-driven association. This past year Pilot dollars funded the following four research teams whose goals are to:

- **Increase our understanding of IC** – Berkley, PhD was awarded funding to study the *Influence of Endometriosis on Bladder Function: Basic Studies in a Rodent Model*

- **Investigate a potential diagnostic tool** – Rodriguez-Saona, PhD, Gilleran, MD, and Buffington, DVM, PhD, received grant dollars for the *Validation of a Rapid and High Throughput Method of Diagnosis of Interstitial Cystitis by Infrared Microscopy*

- **Study osteopathic manipulation as a potential treatment** – Sastry, MD, Sperling, DO, Rejba, RN, Mosiniak, AS, Whitmore, MD, were awarded a pilot grant for the *Osteopathic Manipulation as a Therapeutic Intervention for Female Interstitial Cystitis Patients with High-tone Pelvic Floor Dysfunction*

- **Epidemiologic study** – Warren, MD, Jacobs, MD, Langenberg, MD, Greenberg, MA received funding to continue efforts to conduct a comprehensive analysis of the IC population in their study *Natural History of 314 Incident IC/PBS Cases*
Additionally, in FY2008, the Fishbein Family IC Research Foundation, founded in 1997, disbursed more than $61,000, funding further investigation of the following:

- Antiproliferative factor (APF) – the biomarker unique to people with IC that holds promise as a diagnostic test as well as a treatment.
- Hormones and stress in people with IC – a study of the effects of the hormones prolactin and oxytocin on pain levels. Findings released in 2008 indicate that oxytocin may help to reduce bladder pain and anxiety related to pain.
- Noninvasive bladder testing – examination of specific proteins in IC patients’ urine that are known to be produced in higher amounts. The results could lead to a urine test for IC.
- Genetics links – exploration of IC in multitudes of families to pin down the possible genetic factors of IC.
- Overlapping conditions research – investigation of the relationship of IC with other disorders.

**PROMOTE THE LATEST RESEARCH FINDINGS**

During the past year, the ICA continued to connect researchers and patients through clinical trial recruitment efforts. Blast emails informed patients about clinical trial recruitment opportunities, and www.ichelp.org served as a hub for current IC studies as well as the latest research highlights. Each month the electronic news digest, Café ICA, provided lay summaries of IC research findings from peer-reviewed scientific journals.

Reporting daily from the floor of the 2008 American Urologic Association (AUA) Annual Meeting, ICA email blasts highlighted relevant sessions for four consecutive days. The number of sessions dedicated to IC signified that IC is becoming a much higher priority in urology practice and research. The AUA offered three different courses on IC, a podium session was devoted entirely IC, and the NIDDK announced that it is placing new emphasis on IC research. Two ICA publications recapped highlights of the AUA annual meeting:

**ICA Update** - The Fall 2008 issue explored the most up-to-the-minute IC research developments from the AUA Annual Meeting. The introductory article in the issue, From Research to You, outlined the many steps it takes to get a new IC treatment to the marketplace, gave a short history of IC research efforts and outcomes, and showed how scientists are learning more about IC, even from medical and research failures.

**Professional Perspectives** - The Summer 2008 issue of this scientific newsletter covered AUA research presentations and discussed the relevancy of these new findings to clinical practice and patient care.
As more research is being conducted and education about IC grows, we are finding that much of the past diagnostic history about IC excluded some very significant criteria.

• Gender bender – the female to male ratio for IC is narrowing. Men account for a higher proportion of patients with IC than has previously been recognized.¹

• Many women with IC experienced bladder and bowel problems in childhood.²

• Urinary tract disorders occur more frequently in people with IC, as do GI tract ailments and other chronic conditions beyond the bladder.³

• Sexual dysfunction is high in people with IC.⁴

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ICA advocacy has many facets. We advocate through extensive involvement with the National Institutes of Health (NIH), nonprofit healthcare associations, and Congressional Representatives and policymakers. We also inspire, educate, train, and thus empower many individuals with IC who become activists for the cause, representing IC patients in the media, on Capitol Hill, and at meetings and conferences.

The ICA is present when patient organizations collaborate to ensure that interstitial cystitis is included. And when researchers and clinicians meet to discuss approaches to the study or treatment of IC, the ICA is there to make sure the needs of IC patients become part of the solution.

Provide a Voice for the IC Healthcare Community

As a national advocate for IC patients, healthcare providers, and researchers, the ICA serves as a voice for those with IC, some of whom are too isolated or too sick to speak on their own behalf.

Throughout 2008, ICA government affairs staff met with legislators, educating them about the continued need to advocate for people with IC. In the spring of 2008, ICA Executive Director, Barbara Gordon; Fishbein Foundation President, Laurie Fishbein; Associate Executive Director of the National Vulvodynia Association (NVA), Chris Veasely; and Government Affairs consultant Libby Mullin met with New York Congresswoman Nina Lowery to raise awareness about the overlap of IC, vulvodynia and pelvic pain. Working collaboratively, NVA and ICA submitted language requesting the federal government to dedicate funding to scientific research on the overlap of IC, vulvodynia, and chronic pelvic pain.

Advocacy efforts also focused on the many IC patients who are in chronic pain, which can radically alter the ability to work, affect family and friend relationships, and significantly lower the quality of life. Through collaboration with

President of the Fishbein Foundation, Laurie Fishbein, with New York Congresswomen, Nita Lowey
other nonprofit patient organizations and grassroots efforts, the ICA garnered attention at the federal level for people in pain.

- Better access to pain management is closer to reality because of the National Pain Care Policy Act of 2008 (HR 2994), passed unanimously by the House of Representatives in the fall of 2008. At the close of this ICA fiscal year, the bill was with the Senate Committee on Health, Education, Labor, and Pensions. The ICA continues to actively advocate for passage of this important legislation.

- We called upon the IC community to contact their congresspeople about necessary pain management for long-term chronic pain disabilities for veterans. These efforts helped to pass both the Veterans Pain Care Policy Act (S 2160) and Military Pain Care Policy Act of 2008 (HR 5465) in October of 2008.

We also closely monitored 12 healthcare reform meetings with an ear to the needs of people with IC, as well as the healthcare providers and researchers who strive to help them. Examples include:

- Legislative sessions with Senator Edward Kennedy in Washington, DC: At the beginning of this fiscal year, ICA government affairs consultant, Libby Mullin, participated in a series of meetings with lobbyists and lawmakers hosted by Kennedy with the aim of crafting a “shovel-ready” plan to deliver to the new president. The plan is aimed at providing affordable coverage for all Americans.

- National Health Council (NHC) Government Relations Affinity Group meetings hosted in Washington, DC on a monthly basis: As a member of this coalition, which serves as a powerful voice to people with chronic diseases and disabilities and their caregivers, the ICA has participated in healthcare reform meetings and the development of healthcare reform policy initiatives intended to ensure adequate health coverage for IC patients.

“"It was several years after I returned to Georgia from my tour of duty on the USS Vulcan,” Gulf War veteran Tom Lavender recounts, “that my IC symptoms began.” Tom was diagnosed in 1997 and, once he was able to find a physician experienced in IC, began treatment. His doctor also told him about the ICA. “I became a member of the ICA and began to find the information I had been seeking,” states Tom. He also reached out to inform and comfort other people with IC.

Tom wrote a letter about IC to the editor of his local paper that was published. “My hope was that I would reach people who might have symptoms of the condition and that my story would help them seek medical care,” he recalls. The letter did have an effect. Tom discovered it even helped educate a future doctor. A local young man who was in medical school at the Medical College of Georgia read the letter and began learning more about IC. “Still, there’s a lot of educating to be done,” Tom knows.

Tom would like to see physicians pour more of their energies into research. And he is thankful he is a state employee with health insurance. “If I had no insurance right now, I’d be sweating bullets!” he exclaims.

He is doing better today than he was in 1997. Tom has limitations, but he’s philosophical about them. He can’t travel much, but he quips, “I spent four years in the Navy, so I am not worried about traveling too much.”

But he still has for a wish for all people with IC - a cure.
CRUSADE FOR THE IC PATIENTS

The ICA participated in numerous IC-related research meetings in fiscal year 2008.

**March 31, 2008**
The American Urological Association (AUA) Foundation sponsored the inaugural Patient Advocacy Summit. The Summit brought together more than 20 representatives from 16 patient advocate and direct-service organizations involved in prostate, bladder health and wellness – including Barbara Gordon, Executive Director of the ICA. The meeting’s purpose was to discuss the limited awareness of urologic diseases and sparse funding for urologic research. One outcome of this summit was a proposal to create the Urologic Advocacy Coalition. Although initially the coalition was to focus on prostate health and bladder incontinence, the work done at the summit expanded its purpose to include collaborative work on raising awareness and advocacy for additional research funding in urology.

**March 31, 2008**
The leaders of nine patient advocacy groups representing significant numbers of people with overlapping conditions met in June to discuss the potential of joining forces on the fight for more research dollars and unifying patient advocacy efforts. The represented groups were:

- Anxiety Disorders Association of America
- Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) Association of America
- Endometriosis Association
- International Foundation for Functional Gastrointestinal Disorders
- Interstitial Cystitis Association
- National Fibromyalgia Association
- National Sleep Foundation
Discussions focused on common challenges and the potential value of forming a coalition to jointly raise awareness about comorbid conditions, advocate for research dollars and patient rights, and work to educate patients, healthcare providers, and the public about the phenomenon of overlapping conditions. The meeting concluded with each organization committed to gathering feedback from their constituents on forming the coalition, providing input regarding the potential scope and mission of the coalition, and offering recommendations on initial efforts.

**June 1 - 3, 2008**

The Fifth Scientific Meeting of The TMJ Association focused on conditions often found to be comorbid with temporomandibular joint and muscle disorders (TMJDs). These include chronic headache, generalized pain conditions, irritable bowel syndrome, endometriosis, interstitial cystitis, vulvodynia, fibromyalgia, chronic fatigue syndrome, and rheumatoid arthritis. The goal of the meeting was to discover common roots and physiological pathways among these conditions for further understanding of all of them, and conceivably provide innovative targets for diagnosis and therapy. Because the meeting brought together scientists and clinicians knowledgeable about each of the complex conditions, we hoped to stimulate cross-collaborative studies as a means to accelerate research progress and ultimately benefit patients. Toward that end, the TMJ Association invited young investigators to stimulate their career commitments to engage in TMJD and related research. Patients also participated in panel presentations and discussions, providing opportunities for experts and patients to learn from each other in formal and informal exchanges.

**June 3, 2008**

In concert with the TMJ Association’s scientific meeting, Barbara Gordon attended the Second Overlapping Conditions Meeting held on June 3. Attendees included leaders of key patient advocacy groups representing related chronic pain conditions. Organized by the TMJ and Vulvodynia Associations, the meeting agenda focused on sharing lessons learned in regards to overlapping conditions, as well as potential areas for collaboration.
June 5-7, 2008

The European Society for the Study of IC/PBS (ESSIC) held its annual meeting June 5 through 7 in Rome, Italy. At the meeting, ESSIC, which consists of a small group of primarily European researchers and clinicians, reaffirmed their preference for using the name “bladder pain syndrome” which would eventually replace the name “interstitial cystitis.” Many of the ESSIC members will begin to publish studies about IC under the name bladder pain syndrome/interstitial cystitis (BPS/IC). To help further define and characterize IC, ESSIC announced plans to develop an international database of IC patient profiles. In support of IC patients, Barbara Gordon attended the public sessions held on June 6 and 7.

June 16-17, 2008

The ICA participated in the NIDDK symposium, “Redefining the Urologic Chronic Pelvic Pain Syndromes: A New Beginning,” held June 16 and 17. The purpose of the symposium was to enlist expert opinion related to the multiplicity of factors involved in defining the urologic pelvic pain syndromes. Updates were given on such topics as: classifying urologic chronic pain syndromes, advanced diagnostic studies for characterizing the pain syndromes, epidemiological data for overlap of chronic pelvic pain syndromes, developing biomarkers for the chronic pain syndromes, as well as many other topics. The meeting explored the pros and cons of developing a unifying definition, as well as the need for phenotyping persons with these disorders. Interactive discussions were strongly encouraged among speakers, participants and the panel of consultants. A major outcome was development of a definition of these diseases and their phenotypes, which will be used in future NIDDK-funded research studies and the upcoming network for a Multidisciplinary Approach to the Study of Pelvic Pain.
As awareness and understanding of interstitial cystitis grows, the ability for people with IC to be properly diagnosed, and treated quickly and effectively grows too. In this fiscal year, the ICA further broadened its reach to all audiences.

**EXPAND UNDERSTANDING WITHIN THE HEALTHCARE COMMUNITY**

To speed time to diagnosis, help ensure patients receive the latest treatment, and help healthcare providers understand what it is like to live with IC, we worked diligently to raise awareness among the medical community.

In fiscal year 2008, more than 1,000 healthcare providers received printed versions of the ICA’s publication, *Professional Perspectives*, exposing them to the latest developments in IC research and treatments, as well as other breaking IC medical news. *Professional Perspectives* is a quarterly publication the ICA offers in print and online, free-of-charge, to keep the medical community up-to-date on the latest IC news and information.

By exhibiting and networking at national medical meetings, the ICA also helped more than 16,000 healthcare providers to better understand IC. Both new and seasoned healthcare providers received the latest IC news when they stopped by our exhibits at:

- Society of Urologic Nurses and Associates (SUNA) Annual Conference and Annual Symposium
- American College of Obstetrics and Gynecology (ACOG) Annual Conference
- American Pain Society’s (APS) Annual Meeting
- American Urological Association’s (AUA) Annual Meeting
- Annual Scientific Meeting of the American Urogynecologic Society (AUGS).

Strategically leveraging the power of the medical media, the ICA ran ads in *Urology Times* and *ACOG Today* to maximize our exposure at the conferences and further strengthen our messages. These special issues were distributed to attendees at the annual meetings of the AUA and ACOG, and mailed to all subscribers. *Urology Times* is distributed to 10,652 U.S. Urologists. By placing our ad in the May edition of the publication, the ICA was able to reach an additional 4,000 bonus attendees at the AUA annual meeting. *ACOG Today* has a circulation of just over 51,000, reaching OB/GYNs and other women’s health professionals. For the May issue of *ACOG Today*, we again received a bonus distribution of 5,000 at the ACOG annual clinical meeting. It is our hope that, through healthcare professional outreach projects such as these, both providers and patients will be better served.

IC patient Laurie Elmes, RPh CDE, a pharmacist at Columbus Regional Hospital, in Columbus Indiana, took advantage of the ICA’s PowerPoint presentation *Interstitial Cystitis: What Healthcare Providers Need to Know* and other ICA informational materials for her presentations to the Indiana Medical-Surgical Nursing Association. Additionally, she used these tools to educate her fellow employees at Columbus Regional.

IC made the cover of *Urology Times* in its August 1 edition, which featured the comprehensive article *Urologic Pelvic Pain: Diagnosis and Management*, by Arun Srinivasan, MD; ICA Medical Advisory Board member Robert M. Moldwin, MD; and Jonathan D. Kaye, MD.

The ICA also partnered with the Association of Reproductive Health Professionals (ARHP), to provide continuing medical education sessions to IC healthcare providers and researchers.
In late 2007 and early 2008, Lee P. Shulman, MD and ICA Medical Advisory Board members Robert Moldwin and Kristene Whitmore, each conducted well-attended live webinars using this module.

Approximately 1,100 healthcare providers have participated in the IC continuing medical education (CME) program created in partnership with the Association of Reproductive Health Professionals (ARHP), either at a live session, in a live webinar, or by accessing online archived webinars.

Additionally, the ICA and ARHP developed a number of new educational tools for use by healthcare professionals and patients.

- We produced a new patient Health Matters Fact Sheet, What You Need to Know about IC, in 2008 which is available in English and Spanish.

- We also created a PowerPoint IC medical education slide module with talking points. This presentation was used at 10 national and regional society meeting visiting faculty sessions that were held.

- We generated a special issue of ICA Professional Perspectives, and ARHP developed a Quick Reference Guide for clinicians.

The ARHP dedicated their April 2008 edition of Clinical Proceedings, an accredited clinical monograph, to the subject of IC. Entitled Screening, Treatment, and Management of Interstitial Cystitis/Painful Bladder Syndrome, this medical education tool is primarily used by nurse practitioners, nurse midwives, pharmacists, physicians, physician assistants, and public health professionals.

In August, the National Black Nurses Association hosted its 36th Annual Institute and Conference in Las Vegas, Nevada. Diane A. Smith, MSN, CRNP, who sits on the expert medical advisory committee of the Interstitial Cystitis Association/Association of Reproductive Health Professionals, used the educational module Screening, Treatment, and Management of Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS) to present to a packed room.

**EDUCATE FUTURE PHYSICIANS**

At the American Medical Student Association (AMSA) Regional Conference in Portland, Maine in November 2007, IC patient and nurse, Risa Cohen, RN, presented a breakout session entitled Diagnosis and Treatment of Interstitial Cystitis. The ICA supplied Cohen with the ICA Healthcare Professional PowerPoint presentation and a number of printed materials to hand out. The conference, People Treating People, which targeted both medical and pre-medical students, was hosted by The University of New England College of Osteopathic Medicine.
RAISE AWARENESS OF THE GENERAL PUBLIC

Patient and public education provides valuable opportunities for undiagnosed individuals to consider IC as a possible diagnosis. It also offers new hope and new choices to those already struggling with IC, along with networking and support resources.

In FY 2008, the ICA provided patient education and increased public awareness through a number of channels.

- The ICA Update magazine went to 40,000 people, with issues focused on topics such as pelvic floor dysfunction, compounding pharmacies, new trends in neuromodulation, and IC and overlapping conditions.

- The ICA sponsored three regional patient forums held in Phoenix, Arizona, Tampa, Florida, and Tulsa, Oklahoma. Each forum served as an opportunity to raise awareness about IC, and the special challenges of people living with IC, among the public. Experts in the field (Drs. Daniel Brookhoff, John Forest and Robert Evans) updated audiences on the latest IC treatment and research information.

- More than 500,000 online users accessed free health information on www.ichelp.org. Daily users of the ICA website increased to over 2,100.

- Over 50,000 publications were distributed to patients, healthcare

In 2007, interstitial cystitis was number five among all the items people searched on the information service website of the National Institute of Diabetes and Digestive and Kidney and Urologic Diseases (NIDDK). The third most popular publication the information service sent out was Interstitial Cystitis/Painful Bladder Syndrome. And in 2008 NIDDK published a new, easy-to-read booklet, What I need to know about Interstitial Cystitis/Painful Bladder Syndrome.

“I can’t tell you how much the added support of the ICA has encouraged me and given me a feeling of ‘yes, there is something I can do and a place to get answers.’ My symptoms are manageable for the most part greatly due to informational sources such as ICA Update.” JUDY
providing specific details about IC, treatment options, self-help measures, coping strategies and more.

- ICA’s free online monthly news digest, Café ICA, was sent to 28,000 individuals, keeping them up-to-date on medical highlights, diet issues, self-help and coping, and other news. Thousands more visited our website to view monthly editions of Café ICA online throughout the year.

- More than 500,000 readers learned more about IC from an ICA Champion, a patient or clinician who agreed to be interviewed by national print media outlets.

**IC MEDIA COVERAGE CONTINUES ON LOCAL, NATIONAL AND INTERNATIONAL LEVELS**

**November 2007**

Longtime *New York Times* personal health columnist Jane E. Brody included interstitial cystitis in her November 6th column, *Living with Pain That Just Won’t Go Away*. This was the first of three columns that are being dedicated to chronic pain issues.

*Atlanta Latino*, Atlanta’s free weekly 60-page bilingual (Spanish and English) newspaper published an online article about IC. Outreach to diverse communities is a very important aspect of the ICA’s mission.

The Internet radio show, *Patient Power with Andrew Schorr*, featured an hour-long segment on IC, featuring Dr. Robert Moldwin (pictured below), ICA medical advisory board member.

**EDUCATING THE PUBLIC**

The October 8th, 2007 edition of the *Chicago Daily Herald* featured an in-depth article about IC by Susan Stevens. The article, *40 Bathroom Trips a Day*, includes interviews with two longtime IC advocates and ICA supporters, Rhonda Garrett and Barb Zarnikow. Rhonda is currently an ICA Board member, has been an ICA advocate for many years, and has been featured numerous times in IC media coverage. Barb, who is also an ICA Board member and patient advocate, is the founder and leader of the Northwest Suburban Interstitial Cystitis Support Group of Illinois. Her husband, Eric, also serves on the ICA Board of Directors.
Internationally-known IC expert, Dr. Robert Moldwin, teaches physicians and other healthcare providers about IC.

**December 2007**
The December 1 issue of *Urology Times* features the article *Cyclosporine Shows ‘Dramatic’ Results in Severe Interstitial Cystitis* by Penny Allen, ICA medical writer who is also a freelance medical reporter. Cyclosporine is an immunosuppressant medication that is being considered in the treatment of severe IC.

On December 4, the Internet radio show, *Patient Power with Andrew Schorr*, featured an hour-long segment on IC – again! The producers of *Patient Power* reported that the November 1st show featuring IC was so successful that they scheduled another show on IC for December. It drew an overflow crowd, as well.

**January 2008**
The January 31 edition of the *Tampa Bay Tribune* featured a column on interstitial cystitis by Tribune columnist, Stuart Hart, MD. The article, entitled *Painful Bladder Syndrome May Elude Diagnosis*, featured information about IC symptoms, diagnosis, and treatments, and the story of an IC patient and activist. Dr. Hart is an assistant professor of obstetrics and gynecology in the Division of Urogynecology and Pelvic Reconstructive Surgery at USF Health.

The Monday, January 28, edition of the *Staten Island Advance* featured the article *Interstitial Cystitis: Understanding a Painful Bladder Condition*, by Joanne Lamonica, MD, a practicing urologist from Staten Island, New York.

**February 2008**
In early February, CBS 46 News – Atlanta featured a segment about IC. Interviewed for the story were Kim Waitz and her physician Denise Pecht, MD, both of the Atlanta area. Waitz endured 20 years of misdiagnoses before she received a diagnosis of IC. Dr. Pecht treats over 300 women with IC in her practice.

“I wrote explaining some of the bladder issues I was having and wanted to know if I had IC or not. I went to a urologist about two weeks ago and was finally diagnosed. I just wanted to thank you so much for the info you sent me. I showed it to the urologist and he said he wouldn’t have thought of IC. Since I’ve been diagnosed with something and know it isn’t all just in my head I am so much happier. Again, thank you so much for giving me the answers I was looking for seven years.” Alyssa

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April 2008
An article about IC appeared in the National Fibromyalgia Association’s e-newsletter Fibromyalgia ONLINE. This issue of Fibromyalgia ONLINE was dedicated to conditions such as IC that have been shown through research and anecdotal evidence to occur more often in people with fibromyalgia. Other related conditions covered in this issue include chronic fatigue syndrome, restless legs syndrome, and Sjogren’s syndrome.

May 2008
Fox 29/WFLX, a television station based out of West Palm Beach, Florida, ran the article Chronic Pelvic Pain: Diagnosis and Treatment, on their website. The informative and compassionate article focused on IC, endometriosis, and also other causes of pelvic pain. Emphasizing that chronic pelvic pain is real – not in your head – and can be very debilitating, the article stressed that obtaining the correct diagnosis (or diagnoses in some cases) is the first step in getting relief.

June 2008
In mid-June Paul G. Donohue, MD, author of the popular syndicated newspaper column To Your Good Health, addressed the topic of IC in his response to a question posed by a reader who asked for more information about IC. To Your Good Health appears in newspapers across the country.

July 2008
The Spartanburg, South Carolina Herald-Journal focused on IC in a July feature article. Elizabeth Bozeman, MD, who treats people with IC at The Urology Center in Spartansburg, SC, was interviewed, along with Karen Fann, a nurse with a mild case of IC and Rhonda Greenway, who has the Hunner’s ulcer form of the disease.

The July 29 print and online editions of The Irish Times, out of Dublin, Ireland, featured a question and answer column that talked about IC entitled Check-up with Marion Kerr.

August 2008

The cover story of the August 1 clinical edition of Urology Times features the comprehensive article “Urologic Pelvic Pain: Diagnosis and Management” by Arun Srinivasan, MD; ICA Medical Advisory Board member Robert M. Moldwin, MD; and Jonathan D. Kaye, MD.

Clinical Edge, a syndicated column from Mayo Clinic, featured IC. The column appeared in the Chicago Tribune and the Rochester Post-Bulletin.

September 2008
The September issue of Self magazine discusses IC in an article by Lisa Callahan, MD, entitled Is There a Doctor in the House? The article covers frequently asked women’s health questions.
RESPOND TO PUBLIC INQUIRIES

The ICA’s toll-free telephone hotline and the online IC Question Corner offer one-on-one support and information:

- ICA staff and volunteers responded to more than 800 telephone inquiries from patients, family members, healthcare providers and others in FY 2008.
- Personal responses were sent to 1,000 email messages that came into the ICA web site.
- Approximately 1,800 individuals were matched with IC healthcare specialists through the ICA Healthcare Provider Registry.
- 100 people with IC received personalized assistance from the ICA in navigating the disability system.

SPONSOR PATIENT FORUMS

For two decades, the ICA has sponsored regional patient forums, featuring IC healthcare specialists, and providing education, information and support. In 2008, we sponsored three patient forums - in Phoenix, Arizona; Tampa, Florida; and Tulsa, Oklahoma. Approximately 375 IC patients and their families attended these forums to learn from top IC experts. Those presenting included ICA Board and Medical Advisory Board members, Robert Evans, MD, and Daniel Brookoff, MD, PhD; and IC expert John Forrest. These all day, interactive affairs also provided a great opportunity for patients and their families to network and gain support.

PROVIDE 24/7 ACCESS TO HEALTH INFORMATION

Thousands of people with IC, as well as their friends and loved ones, continue to rely on and trust the ICA’s communication tools: the ICA Update quarterly magazine, Café ICA online monthly news digest, and the ICA website www.ichelp.org.

RUNNING TO SUPPORT IC PARTNERS

ICA Champions Joe Daczko and Angi Daczko, both from Ohio, were thrilled to announce that Joe took on the Boston Marathon in March in the name of all people suffering from IC. Angi, who has IC, noted that Joe ran the race wearing a t-shirt emblazoned with “This pain stops. Theirs doesn’t.”

Connecticut resident Michelle Noehren, whose younger sister Debra struggles with IC and several other medical issues, ran the Delaware Marathon in May in honor of her sister. Michelle raised nearly $500.00 during her marathon training which she donated to the ICA in Debra’s name.

“I just want to say THANK YOU for such an informative website! I found your website and diagnosed myself. Thank you, thank you, thank you. I feel like FINALLY I have some hope!” SS
ENSURE SOUND FISCAL PRACTICES

Programs and Service $1,472,121

Administration $193,622
Fundraising $167,153

- Patient Forums $7,964
- Combined Federal Campaign $25,072
- Sale of Resource Materials $164,999
- Memberships / Subscriptions $167,917
- General Donations $476,741
- Other Restricted Donations $422,557
- Federal Grant $529,901
The following is a summary of the financial statements incorporated in the annual audit report issued by Councilor, Buchanan & Mitchell, P.C. for the year ended September 30, 2008. The complete financial statements and notes are available upon request from ICA.

## STATEMENT OF FINANCIAL POSITION - SEPTEMBER 30, 2008

### ASSETS

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<thead>
<tr>
<th>Current Assets</th>
<th>Current Liabilities</th>
<th>Net Assets</th>
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<td><strong>Cash and Cash Equivalents</strong></td>
<td><strong>Accounts Payable and Accrued Expenses</strong></td>
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<td><strong>Certificates of Deposit</strong></td>
<td><strong>Deferred Lease Liability</strong></td>
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### PROPERTY AND EQUIPMENT

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### OTHER ASSETS

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<th><strong>Total Assets</strong></th>
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<td><strong>$4,599</strong></td>
<td><strong>$1,092,932</strong></td>
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</tbody>
</table>

## STATEMENT OF ACTIVITIES - FOR THE YEAR ENDED SEPTEMBER 30, 2008

### SUPPORT AND REVENUES

| General Donations | **$476,741** | **$476,741**               |
| Membership / Subscriptions | **$167,917** | **$167,917**               |
| Sale of Resource Materials | **$164,999** | **$164,999**               |
| Administrative Cost Revenue | **$40,611** | **$40,611**               |
| Research Fees | **$7,268** | **$7,268**               |
| Forums | **$7,964** | **$7,964**               |
| Combined Federal Campaign | **$25,072** | **$25,072**               |
| Other Restricted Donations | - | **$49,843** | **49,843** |
| Research and Research Related | - | **$109,694** | **109,694** |
| Public Health Education | - | **$511,050** | **511,050** |
| Patient Services | - | **$227,622** | **227,622** |
| Professional Health Education and Training | - | **$6,370** | **6,370** |
| Net Assets Released from Restrictions | **$918,406** | **$918,406** | **$918,406** |
| **Total Support and Revenues** | **$1,808,978** | **$1,808,978** | **$1,795,151** |

### PROGRAM SERVICES EXPENSES

| Research | **$148,484** | **$148,484**               |
| Public Health Education | **$198,836** | **$198,836**               |
| Professional Health Education and Training | **$415,933** | **$415,933**               |
| Patient Services | **$708,868** | **$708,868**               |
| **Total Program Services Expenses** | **$1,472,121** | **$1,472,121** | **$1,472,121** |

### SUPPORTING SERVICES EXPENSES

| General Administration | **$193,622** | **$193,622**               |
| Fund-Raising | **$167,153** | **$167,153**               |
| **Total Supporting Services Expenses** | **$360,775** | **$360,775** | **$360,775** |
| **Total Expenses** | **$1,832,896** | **$1,832,896** | **$1,832,896** |

### Changes in Net Assets

| Investment Income (Loss) | **($4,086)** | **$4,086** | **$4,086** |
| Net Assets at Beginning of Year | **$646,726** | **$366,198** | **$1,012,924** |
| **Net Assets at End of Year** | **$618,722** | **$357,338** | **$976,060** |
The work of the ICA is made possible through the generosity and vision of individuals, as well as foundations and corporations. Donations help us to keep program and services operating at peak strength, so that every IC patient who needs help can have it, no matter where he or she may live, no matter how disabled they may be.

Our sincerest gratitude to all who made generous gifts throughout FY2008.

The following gifts were received for Fiscal Year Ending September 30, 2008 (October 1, 2007 through September 30, 2008).

**FOUNDATIONS, ASSOCIATIONS & TRUSTS**

Thanks to those whose generosity allows the ICA to further achieve its mission.

Amador Community Foundation
Astellas USA Foundation
Louis Berkowitz Family Foundation, Inc.
Boeing Charitable Trust
BP Fabric of America Fund
Charlesmead Foundation
Citigroup Global Impact Funding Trust
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Medtronic Foundation
MGM Mirage Voice Foundation
Oklahoma City Community Foundation
Pathways Main Street United Methodist Church
Karen & Christopher Payne Foundation
PIMCO Foundation
Schwab Fund for Charitable Giving
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Vanguard Charitable Endowment Program

**ONLINE NETWORKS FOR GIVING**

Our thanks to the following online giving sites and to those who gave to the ICA through them.

**EMPLOYER MATCHING GIFTS & GIVING CLUBS**

Thanks to employees and employers alike who support the ICA through Matching Gifts and Giving Clubs.

AIG Matching Grants Program
Carmax Foundation
Clorox Company Foundation
Illinois Tool Works Foundation
Merck Partnership for Giving
Microsoft Giving Campaign
Pfizer Foundation Matching Gifts Program
Prudential Foundation Matching Gifts
Wachovia Foundation Matching Gifts Program

**FEDERAL AGENCIES**
Federal Agencies help the ICA to increase awareness about IC. Special thanks to the:

Centers for Disease Control and Prevention
National Institutes of Health

**CORPORATIONS**
The ICA is grateful for the ongoing support that we receive from our corporate sponsors.

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Allergen
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Farr Laboratories, LLC
Kingdon Capital Management, LLC
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Our thanks to the artists who donated their time and talents to the ICA Update magazine.

Melynn Allen
Dr. Diana Dunn
Janet Kozachek

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Harriet Burke  Peggy Cook  Joan Dick
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<td>Nerina Lazaric</td>
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<td>Honey Lee</td>
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<td>Bonnie Lee</td>
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<td>Deirdre Lee</td>
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<td>Janet Leitch</td>
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Interstitial Cystitis Association

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