Founded in 1984, the Interstitial Cystitis Association (ICA) is the authoritative source of interstitial cystitis (IC) information in the United States.

The ICA:

- Provides the most comprehensive and up-to-date information on IC
- Offers IC patients, their families, and friends support
- Educates the medical community and the public about IC
- Represents patients and advocates for research funding
- Provides pilot research funding to find effective treatments and a cure for IC

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The Interstitial Cystitis Association

A Year of Transformation

Annual Report for Fiscal Year Ending September 30, 2007
October 1, 2006 to September 30, 2007

Embracing Fresh Approaches and a New Face ........................................... 3

Advocating for People with IC ................................................................. 4
  Research
  Recognition
  Understanding

Taking Awareness to New Levels ............................................................... 10
  Patients and Public
  Health Professionals

Empowering People with IC ....................................................................... 16
  Information
  Support

Appreciating Your Generosity .................................................................... 20
  Foundations
  Federal Agencies
  Corporations
  Artists
  Major Individual Contributors

Ensuring Sound Fiscal Practices ................................................................. 28
  Financial Highlights Fiscal Year Ending 2007

Achieving Mission Impact .......................................................................... 30
  Board of Directors
  Medical Advisory Board
  Staff, Consultants, and National Patient Support Advocates

Honoring Vicki Ratner, MD, Founder and President Emeritus .................. 32
IC patient and ICA board member Rhonda Garrett and her son.

ICA staffers and their European associates help educate healthcare providers at professional meetings.
Embracing Fresh Approaches and a New Face

Last year’s annual report discussed the growth of the Interstitial Cystitis Association (ICA)—an upsurge made possible through your generous contributions. The ICA entered Fiscal Year Ending September 30, 2007, energized and with new ideas. *The Interstitial Cystitis Association: A Year of Transformation* showcases different ways of thinking, fresh approaches, and a new face.

**Research highlights reflect a different way of thinking about IC.**

Researchers found that IC does not travel alone, and patients often have other problems, such as irritable bowel syndrome and fibromyalgia. It was also found that symptoms of IC—pain, urgency, and frequency—are more common in men than urologists thought.

A group of researchers, mostly from Europe, proposed to change the name of IC to “bladder pain syndrome.” The proposed definition of bladder pain syndrome excludes many IC patients. Also, changing the name could delay diagnosis and complicate insurance reimbursement and disability coverage. After surveying members, the ICA worked to try to persuade these researchers that a name change would not be in the best interest of people with IC.

**Awareness efforts embrace a fresh look and target new audiences.**

With the goal of reaching new audiences and expanding efforts to raise public awareness about IC, we revamped the ICA website and key publications. Working collaboratively with a new partner, the Association of Reproductive Health Professionals (ARHP), the ICA also developed programs to help allied health professionals better recognize and treat IC.

Representing nine states, 23 advocates, including Hollywood actor Paul McCrane, best known as *ER’s* Dr. Romano, visited congressional offices of 19 House representatives and 16 senators to ask for research funding and increased attention to IC. A record effort for the ICA, more members of Congress than ever before were made aware of IC patients’ needs and the importance of a robust IC research program.

**Vicki Ratner steps down and the ICA welcomes a new Executive Director.**

After almost 25 years as the ICA’s guiding force, Vicki Ratner, MD, stepped down from her positions as ICA President and Chief Medical Officer. The ICA is profoundly grateful to Dr. Ratner for her tireless efforts on behalf of IC patients worldwide. Her work has had direct impact on the quality of life for all people with IC. From its beginnings in her living room at a time when very few clinicians were aware of IC, the ICA has grown to become the authoritative and highly respected advocacy organization it is today, and with Dr. Ratner’s constant encouragement there now exists a large international group of superb clinicians and researchers dedicated to studying and treating IC.

Barbara Gordon, MBA, RD, is the new ICA Executive Director. Drawing upon a wide range of healthcare and managerial experience, as well as a deep understanding of the special challenges confronting people who suffer from chronic diseases, Gordon fully embraces the goal of the ICA to give hope to countless IC patients around the world.

Much gratitude to the members of the ICA for believing in and supporting our cause. We thank all of you for your contributions in fiscal year ending September 30, 2007 (October 1, 2006 through September 30, 2007). For those of you who are not yet members, we hope that the mission of the ICA and the accomplishments detailed in this report inspire you to join the Interstitial Cystitis Association. We value your support, and we encourage your involvement.
Advocating for People with IC

More than 1.2 million, and almost certainly many, many more Americans have IC.

New estimates put the annual cost of caring for people with IC at $66 million, placing it in the top 10 most costly urologic diseases. The resources committed to researching, treating, and searching for a cure are wholly inadequate. That is why educating those who can make a difference in researching, recognizing, understanding, and treating IC is central in the work of the ICA.

This year, highly successful ICA advocacy efforts provided significantly more resources for research and IC education. In the process, new ideas for IC research were generated, and clinicians renewed their commitment to high-quality care.

Research

The ICA continued to administer two pilot research grant programs—the Fishbein Family IC Research Foundation and the ICA Pilot Research Program. As a result of ICA advocacy, Congress directed the NIH to devote resources to IC research and to seek research projects that offer new approaches.

Fishbein Family IC Research Foundation Yields Results

We are pleased to report that researchers are steadfastly pursuing investigations into the many aspects of IC, from possible causes to potential therapies. Of note, genetic studies are currently under way throughout the world, stimulated and supported by the Fishbein Family IC Research Foundation.

The research projects funded recently by the Fishbein Foundation kept research attention focused on developing a test for IC and understanding the mechanism by which antiproliferative factor (APF) controls bladder cell growth. Grants generously funded by the Fishbein Foundation and administered by the ICA include the following two key studies:

- **P53 as a Downstream Mediator of Signaling by Antiproliferative Factor (APF).** Principal Investigator Jayoung Kim, PhD, continued investigation of the APF protein, which is elevated in the urine of people with IC.

- **Autoantibody Signatures as Biomarkers of Interstitial Cystitis.** The work of Principal Investigator Brian Liu, PhD, in autoantibody screening has been widely published and shows much promise in potential non-invasive testing for IC.

Work was completed on grants funded in previous years: Jordan Dimitrakov MD’s project, **Candidate Gene Identification in Interstitial Cystitis** was cofunded with the ICA in 2004. It showed enough promise that it has since received NIH funding. His work found cumulative linkage data strongly suggesting that there is a genetic component to IC, and mutations in at least three to five different genes may be responsible. Because several different genes are implicated, researchers pursuing new pharmaceutical treatments have a variety of approaches to pursue.

ICA Pilot Program Makes a Difference

The ICA continued its own research efforts with the **Measurements and Evaluation of Trends Relevant to Interstitial Cystitis** (METRIC) survey, an epidemiologic study that will lay foundations for better patient care and further research. Important findings on the impact of IC on patients were presented at a national, scientific meeting in the fall of 2007.

AUA Foundation Scholar, Wujiang Liu PhD, received funding to investigate the role of mast cells in antigen-mediated autoimmune cystitis.
2007 Research Highlights

Research conducted in 2007 changed our thinking about IC:

- Research confirmed that IC doesn’t travel alone, and that patients often have other problems such as irritable bowel syndrome and fibromyalgia.
- The symptoms of IC—pain, urgency, and frequency—are more common in men than urologists have thought.
- Researchers explored the cost of IC, and found it to be much higher than that of many other chronic illnesses such as peripheral neuropathy, low back pain, fibromyalgia, or rheumatoid arthritis.
- Research at the cellular level continued. The basic science of APF took a big step forward this year with discoveries about its role in cell growth and division and its relationship with a known regulator of cell function.
- Many innovative treatments for IC were further developed this year. Oral medications, bladder instillations, external and internal stimulator devices, and hands-on interventions advanced along the pipeline, all with the potential to provide better IC symptom relief.

ICA Study Shows Personal Impact

Researchers from the National Opinion Research Center (NORC) at the University of Chicago presented the first results from the NORC/ICA METRIC epidemiology survey at the American Public Health Association’s 135th Annual Meeting and Exposition in Washington, DC.

The study was based on nearly 3,000 responses to a 28-page survey that gathered information on IC patients’ life experience. The study found that:

- 40 percent of respondents reported low self-esteem as a result of IC.
- 42 percent believed that IC caused them to “miss out on life.”
- 31 percent admitted that IC led them to have suicidal thoughts.
- 22 percent noted that IC has caused them to lose close, meaningful relationships.
- 66 percent said IC had negatively affected intimacy and 71 percent noted pain during sexual activity.
Advocating for People with IC

Fresh ideas and research directions are expected to come from the MAPP initiative, a collaboration of expert urologists who study IC and chronic prostatitis with rheumatologists, neurologists, gastroenterologists, and other experts who study fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome, and other overlapping conditions.

Working Collaboratively on NIH Research Efforts

The ICA worked to shape NIH-sponsored clinical trials. Dr. Ratner served on two NIH advisory committees, one for the Interstitial Cystitis Clinical Research Network (ICCRN) and the other for the RAND Interstitial Cystitis Epidemiology (RICE) study.

- The ICCRN launched trials of two new potential treatments: mycophenolate mofetil (CellCept), an immunosuppressant drug, and physical therapy. Early results of the CellCept trial were disappointing, and the study was discontinued. The results of the physical therapy trial, however, offer promising results for relief of IC symptoms.

- As a member of the RICE oversight committee, Dr. Ratner worked to keep the NIH-funded, five-year national study focused on the interests of people with IC.

ICA advocacy efforts also prompted a new NIH study, the Multi-disciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network. The MAPP initiative is sponsored by the National Institutes of Diabetes and Digestive and Kidney Diseases (NIDDK), together with several other NIH institutes.

The NIH has committed up to a total of $7.5 million dollars per year over five years, starting in the summer of 2008, to fund six research centers that will study the relationship of IC with other chronic conditions, like irritable bowel syndrome, that often overlap.
Recognition

ICA advocacy efforts led Congress to recognize the importance of providing accurate and up to date information about IC to the public and healthcare professionals and to form a partnership between the ICA and the Centers for Disease Control and Prevention (CDC) to promote better awareness of IC.

Our thanks to the CDC for working collaboratively with us. This partnership has allowed the ICA to address professional audiences we had not reached before, such as obstetrician/gynecologists and urogynecologists. CDC funds also helped to:

- Expand public education initiatives, including national media coverage of IC in consumer magazines, radio, and television.
- Enhance web presence, including an updated website and an educational video about IC placed on YouTube.
- Revise the format and broaden the distribution of the quarterly magazine, the ICA Update.

ICA Advocate of the Year Award

Susan Keay, MD, PhD, Professor of Medicine in the Division of Infectious Diseases at the University of Maryland Medical Center in Baltimore, Maryland, was named the 2007 ICA Advocate of the Year.

Dr. Ratner presented the award in May 2007 at the Society of Women in Urology meeting, held during the American Urologic Association’s annual meeting in Anaheim, California.

Dr. Keay was recognized for her longstanding support of the ICA and for her years of promising IC research. Among her many discoveries is antiproliferative factor (APF) which is found in the urine of people with IC. It is hoped that APF will be useful as a diagnostic tool.

Our thanks to Dr. Keay for her significant findings, and to the Fishbein Family IC Research Foundation for funding her pilot research.
Patients Have Record Impact on Capitol Hill

Representing nine states, 23 advocates, including Hollywood actor Paul McCrane, best known as ER’s Dr. Romano, visited the offices of 19 House representatives and 16 senators to ask for increased research funding and attention to IC. This was a record effort for the ICA, making more members of Congress than ever before aware of IC patients’ needs and the importance of a robust IC research program at NIH.

“Because of the efforts of IC patients, policymakers on Capitol Hill are recognizing and more aggressively addressing the challenges chronic pain patients face from a fractured healthcare system that limits access to the multi-modal therapies patients need and from the Social Security Administration’s bureaucracy in granting disability benefits. Our advocates have also helped legislators recognize the need to influence the direction of federal research so that NIH is investing in future therapies and cures for these intractable conditions,” said Government Affairs Consultant Libby Mullin.

Representative Nita Lowey (D-NY 18th), a member of the House Committee on Appropriations, who is a strong advocate for women’s issues and for biomedical research and who has supported the ICA’s efforts for many years, spearheaded the effort to place language in the House appropriations bill that would continue the NIDDK IC research effort and keep funding the CDC/ICA cooperative agreement. Her office also collected signatures from her House colleagues on a letter to CDC Director Julie Gerberding, MD, congratulating the CDC on the success of the awareness campaign and urging her to continue the partnership with the ICA.

On the Senate side, the ICA’s strongest voice for patients and for research continues to be Majority Leader Senator Harry Reid, who negotiated language similar to that of the House in the Senate appropriations bill. His steadfast support for IC over the last decade led Congress to appropriate millions of dollars for IC research and has prompted unprecedented efforts to educate health providers about the disease.

Language in both the House and Senate versions of the bill directed the NIH and the CDC to continue to advance their commitments to IC research and awareness and to work with the ICA to do so.
Understanding

Key to the ICA’s 2007 advocacy efforts was giving patients a voice in the medical community on the issue of renaming IC.

A group of mostly European researchers proposed to change IC to “bladder pain syndrome.”

Experts Discuss Impact of Renaming IC

The impact of a name change on patients was a great concern for the ICA:

- It could negatively affect patient care due to a lack of understanding by doctors, insurers, and the public that bladder pain syndrome is IC.
- Many patients thought that the term “bladder pain syndrome” might not convey the severity of their condition to the medical community and health insurance companies.
- The name change could also undermine patients’ efforts to get insurance and disability coverage.

To address these issues, the ICA and the ARHP sponsored a conference, the Definition Meeting of Interstitial Cystitis/Painful Bladder Syndrome Experts, to discuss the proposed name change.

Meeting findings were made available in a white paper entitled, Outcome of the Washington, DC, Consensus Meeting on Interstitial Cystitis/Painful Bladder Syndrome: A Multidisciplinary Meeting of Researchers, Clinicians, and Patients, and in a special issue of the ICA Update.

Internet Survey Gives People with IC a Voice

Through an international Internet survey Michael Chancellor, MD, Director of the Fishbein Family Foundation CURE-IC Program, asked people with IC to contribute their opinions regarding the proposed name change. Distributed through IC databases globally, 2,347 people spoke their minds about the issue.

- The overwhelming majority opposed the proposed name change: 2,187 (93.2 percent) did not believe there was a compelling reason to change the name at this time.
- In addition, 97.8 percent of responders indicated that they should have a voice in this decision-making process. ICA advocacy gave them that voice.
The resources committed to the CDC/ICA cooperative agreement spurred expanded outreach initiatives:

- Briefing editors at major women’s and health media outlets to expand and inform media coverage of IC
- Producing and distributing radio, TV, and online public service spots
- Redesigning of many of the ICA key communication tools

**Patients and the Public**

In the past, the ICA communicated with its patient community through occasional national patient meetings, a quarterly two-color newsletter, and the website. Past media coverage often did little more than show the public the debilitating nature of the disease.

In this year of transformation, the ICA hosted regional forums, converted to a quarterly full-color magazine, and redesigned the website. News stories educated the public about a spectrum of effective treatments.

**Regional Forums**

The ICA reached out and sponsored regional forums on both coasts and in the heartland.

- **Bethesda, Maryland:** Two of the most renowned IC clinicians—both ICA Medical Advisory Board members—kicked off the series: Urologist Robert Moldwin, MD, and pain management specialist Daniel Brookoff, MD, PhD.
- **Los Angeles, California:** Dr. Moldwin was the key speaker and spoke to patients, family members, and friends on the west coast.
- **Detroit, Michigan:** Urologist and ICA Medical Advisory Board Member, David Burks, MD, paired with nurse practitioner Donna Carrico, updated the audience on the latest treatment approaches.
Health Information Resources

The ICA focused on enhancing patient and professional health education materials:

- The ICA Update underwent a transformation from a two-color newsletter to a full-color magazine with even more informative articles and with dissemination expanded beyond the ICA’s membership to physician offices.
- The ICA’s publication for healthcare professionals, Professional Perspectives, was also revamped to make it a more effective tool for professional education.
- Patients and professionals could access information more quickly on the redesigned, easier-to-navigate ICA website at www.ichelp.org.

Deskside Briefings

Through a series of “deskside briefings” with the editors of major health and women’s magazines, the ICA worked to enhance media coverage of IC.

In the past, articles in consumer publications and newspapers depicted IC as a debilitating illness, but often did not offer a wide range of information about support services or places to go for more information.

Ten briefings quickly produced articles in large-circulation magazines, allowing the ICA to inform readers that there are effective treatments for IC and that the ICA offers support:

- Health (1.5 million readers)
- Family Circle (3.8 million readers)
- First for Women (1.4 million readers)

In addition, the April 1, 2007 edition of Woman’s Day featured the story of an IC patient and her sister. In “It Was Worse Than Childbirth,” Michelle McDuffee described her own battle with IC and the sadness she felt when her sister Mia Eddy was also diagnosed with IC.
Getting IC in the Radio, TV, and New Media Spotlight

The CDC/ICA cooperative agreement provided the resources for the ICA to reach millions of listeners and viewers with informative TV, radio, and Internet public service announcements. Dr. Moldwin and IC patient Mary Ellen Altieri, a registered nurse, were the “talent,” and Dr. Moldwin’s office served as the “set.”

The TV spot aired on the American News Network’s Consumer Edition, a weekly half-hour program on the latest developments in consumer, health, and hi-tech news. Over four days, the spot also aired on the DirecTV’s “entertainment” and “female” clusters of stations.

Radio Health Journal’s IC audio news release aired for a week on 446 affiliate stations, reaching 20 of the top 25 US markets.

The video spots reached thousands more on YouTube and Google Video. Only 48 hours after its posting, the YouTube spot had been viewed 2,240 times and was given a five-star rating by viewers.
Patient Activists Go Public

Dedicated and determined ICA patient activists took the initiative to publicize IC. They participated in and organized public events where they and IC were visible, got news coverage of their efforts, and wrote about their experiences in blogs and books.

Marguerite Guzmán Bouvard, Author

With her new book, HEALING: A Life with Chronic Illness, writer and IC patient Marguerite Guzmán Bouvard, of Massachusetts, gave IC patients and anyone with chronic illness a practical and spiritual guide to living well. This deeply insightful memoir offers thoughtful guidance on how to heal the spirit and build a new, full life in the framework of chronic illness. Reviews and blogs of the book, published by University Press of New England, raised awareness about IC and recognized the work of the ICA.

Lucy Lehner, Registered Nurse

Lucy Lehner, RN, and her son, Chase, cycled more than 400 miles in the Great Ohio Bicycle Adventure (GOBA) to help get the word out about IC and raise money for the ICA. Lucy educated her fellow riders and the people in her hometown through a blog and a letter to the editor of the Marion Star.

Barb Zarnikow, Support Group Leader

Chicago IC patient Barb Zarnikow, founder and leader of the Northwest Suburban Interstitial Cystitis Support Group of Illinois, helped get coverage of IC in the Chicago-area’s largest suburban newspaper, the Chicago Daily Herald. The article, “40 Bathroom Trips a Day,” included interviews with her and ICA Board member Rhonda Garrett of Florida.

Phil Clark, Mustang Designer

Although few have ever heard of Phil Clark, nearly every American recognizes his work. In the early 1960s he was a designer of the Ford Mustang and creator of the iconic automobile’s running pony emblem. In addition to his achievements as a designer, a journal documents his struggling with IC. On discovering her deceased father’s drawings, journals, and other memorabilia, his daughter, IC patient Holly Clark, dedicated herself to creating the Phil Clark Foundation. The Foundation is documenting Phil Clark’s role in car history and is raising funds and awareness for the disease that made his life difficult and painful and whose misdiagnosis helped lead to his early death.

Norma Kellam, Spanish Translator

California IC patient and longtime ICA volunteer Norma Kellam worked diligently throughout 2007 with the Spanish language news community to get the word out about IC. She facilitated publication of an informative IC article in Monitor Hispano, a weekly Arizona Hispanic newspaper with a readership of 78,000, and in Atlanta Latino, Atlanta’s free weekly bilingual (Spanish and English) newspaper reaching more than 30,000. Norma also translated for Spanish speakers who contacted the ICA. ¡Muchas gracias, Norma!
Using comprehensive continuing medical education programs and online training tools, the ICA raised awareness among more healthcare professionals than ever before. These programs are an important addition to the ICA’s existing healthcare provider outreach activities. As in the past, Dr. Ratner and ICA staffers spoke at numerous medical professional meetings and distributed ICA publications to professionals.

**Health Professionals**

The CME was presented by visiting faculty members at ten national and regional society meetings, as well as online during three webinars.

**Program Components**

- White paper: *Definition Meeting of Interstitial Cystitis/Painful Bladder Syndrome Experts*
- PowerPoint module with talking points
- CME monograph: ARHP Clinical Proceedings
- Cheat sheet: ARHP Quick Reference Guide for Clinicians
- Patient information: ICA English and Spanish language booklets

**Online Tools**

The ICA produced the first in a new series of online medical education tools to help healthcare professionals become familiar with all aspects of IC.

The presentation, *Interstitial Cystitis: What Healthcare Providers Need to Know*, was designed to further educate the nursing community about IC. The presentation is available free of charge and can be viewed on the ICA’s website at www.ichelp.org

**Continuing Medical Education (CME) Programs**

In the fall of 2007, the Association of Reproductive Health Professionals (ARHP) and the ICA launched a joint education program, *Screening, Treatment, and Management of IC/PBS (Interstitial Cystitis/Painful Bladder Syndrome): A Medical Education Program for Health Care Providers and Their Patients*.

This comprehensive program offers CME modules and associated activities and materials that help physicians, nurse practitioners, physician assistants, nurse midwives, pharmacists, and other professionals better recognize and treat IC/PBS.

**Scientific Forum**

With the NIDDK, the ICA cosponsored one of the most important scientific meetings on IC worldwide, the 2006 International Symposium: *Frontiers in Painful Bladder Syndrome and Interstitial Cystitis*.

The leading newsmagazine for urologists, *Urology Times*, published information from the conference including a front-page feature that took a comprehensive look at the proposal to rename IC.
National and International Medical Meetings

At professional meetings around the world, the ICA reached out to more medical professionals than ever before. Dr. Ratner spoke to more than 200 clinicians from Asia, Europe, and the United States at the Second International Consultation on Interstitial Cystitis-Japan. Dr. Ratner also shared lessons learned in Kyoto, Japan at the newly formed Comfortable Urology Network patient meeting.

On the home front, at regional and national professional meetings, the ICA had booths in exhibit halls, where ICA staff provided healthcare professionals with literature and discussed the latest IC treatments and research. Those efforts took IC information beyond the community of urologists to urologic nurses, urogynecologists, gynecologists, osteopathic physicians, and others.

Educating Healthcare Professionals

American Urological Association
Annual Meeting
Anaheim, CA

American Urogynecologic Society
Annual Meeting
Hollywood, FL

American College of Obstetricians and Gynecologists
2007 Annual Meeting
San Diego, CA

Disorders of the Bladder, Bowel, and Pelvic Floor Symposium
Colorado Springs, CO

Massachusetts Osteopathic Society
Continuing Medical Education Meeting
Boston, MA

Society of Urologic Nurses and Associates
Annual Symposium
Phoenix, AZ

Society of Urologic Nurses and Associates
Annual Meeting
Kansas City, MO
Empowering People with IC

A key part of the ICA’s mission is to empower people with IC. We do that by providing the information and knowledge needed so they can effectively consider their treatment options with their healthcare providers. Educating physicians and other medical professionals about the special needs of people with IC empowers them further.

With Information

Information is the most powerful tool people can have to improve their health and the quality of their lives. The ICA has been the leader in getting up-to-date information to people living with IC.

Health Education Materials

This year, the ICA provided more useful and practical information.

- Articles in the quarterly magazine, ICA Update
- Monthly news-in-review in the electronic ezine, Café ICA
- A new Because You Care series booklet, Being Your Own Best Advocate, offering tools to manage critical life and healthcare issues and related conditions in addition to treatments for IC and inspiration from determined and compassionate fellow patients

Critical Issues, Eye-catching Delivery

In 2007, ICA health information materials covered critical issues, empowering people with IC with information on:

- How to handle the loss of health insurance
- How to apply for Social Security Disability Insurance
- How chronic fatigue syndrome research is transforming its treatment and inspiring new approaches to IC
- What the best treatments are for IC pain
- How to be your own best advocate with doctors, hospitals, and insurers
- How the first approved treatment for fibromyalgia could help people with IC
- How a change in the name of the disease could affect insurance coverage and treatment
- How two creative artists who made outstanding contributions to American culture live and work with IC
Healthcare Professionals Arm Patients with Answers

The ICA Regional Forum series allowed more patients around the country to learn about the latest treatment approaches and get advice directly from the IC community’s best experts.

- At the first of this new forum series, held in Bethesda, Maryland, patients from the mid-Atlantic region got advice and help from two of the most renowned IC clinicians, ICA Medical Advisory Board members Dr. Moldwin and Dr. Brookoff. Dr. Moldwin urged participants to seek treatment for IC as well as related conditions and to be involved in their care. Dr. Brookoff also encouraged participants to demand the help they need, acknowledged that IC pain can be severe, and outlined innovative therapies for IC pain.

- In Los Angeles, California, Dr. Moldwin spoke to West Coast patients, their families, and friends. Actor Paul McCrane, IC advocate and ICA supporter, was on-hand and helped to create a very intimate, inspirational atmosphere at the forum.

- In Detroit, Michigan, Midwest patients got help and advice from ICA Medical Advisory Board member David Burks, MD, and nurse practitioner Donna Carrico. Dr. Burks talked about his specific aims in the treatment and research of IC, and Carrico spoke of her work with IC patients at William Beaumont Hospital’s Women’s Initiative for Pelvic Pain and Sexual Health (WISH) program. She discussed the DVD, Guided Imagery for Relaxation in Women with Pelvic Pain or IC, which was developed at WISH.

To make these experts’ perspective and advice available to even more patients around the country, the ICA produced DVDs and transcripts of these forums.
With Support

Patients’ need for one-on-one advice and support is strong, and the ICA toll-free telephone hotline and online email services continue to meet this need.

Response to Public Inquiries

In the last year, the ICA responded to:

- More than 8,000 inquires from patients, families, and friends of people with IC, providing personal responses to the 125 to 150 calls per week and nearly 100 emails per month received in the Question Corner of the ICA website.
- About 2,500 inquiries from treating healthcare professionals, fulfilling 150 to 200 publication requests per month.

Actor Speaks Out About IC

No IC patient would wish their disease on someone else, but they know that when a well-known personality has IC, it focuses public attention on it. Many have long wished for someone like that to step forward.

In 2007, actor Paul McCrane, best known for his role as Dr. Romano in the TV drama *ER*, made public that he has IC. Surgery, appropriate in only a few severe cases such as his, improved his health so that he could devote some of his considerable talent and energy to raising IC awareness and lobbying on Capitol Hill for research and awareness programs.

McCrane’s story of his 15-year struggle with severe pain, misdiagnoses, dismissive treatment, and the profound effects on his mental well-being and daily life helped validate how severe and painful IC can be and made a powerful case for legislators, researchers, and clinicians to put more resources into research, treatment, and awareness.

Inspiration and hope also radiate from his story, which demonstrate the emotional and spiritual transformation that empowered him to meet the challenge and dedicate himself to helping others with IC.

“I wish none of us had to deal with this. But we do, we do. So, let’s do whatever we can to support each other and support those who are trying to help us.”
During the past year, the ICA disseminated more than 300,000 publications to patients, family and friends, and healthcare professionals. Of those publications, the six most popular titles were the brochures developed by ICA staff:

- Interstitial Cystitis
- IC & Diet
- IC & Men
- IC & Self-Help
- IC & Sexuality
- Vulvar Pain

**Internet Outreach**

A newly designed ICA website welcomed current users as well as more than 175,000 new visitors this past year.

Most users found www.ichelp.org through search engines. Of the 61% of users entering through that path, 44% percent were directed from Google, 10% from Yahoo, and the remaining 7% from other search engines.

The top five key word searches were:

- Interstitial cystitis
- Interstitial cystitis diet
- Interstitial Cystitis Association
- Interstitial cystitis, condition, treatment
- IC

Though the majority of users were English speakers, the languages that visitors configured on their computers included many European languages, as well as Japanese.
Appreciating Your Generosity

Our sincere gratitude to the numerous individuals and organizations who made the ICA’s work possible through their generous gifts. The following gifts were received for Fiscal Year Ending September 30, 2007 (October 1, 2006 through September 30, 2007).

Foundations, Associations, and Giving Clubs
Thank you to the all whose generosity allows the ICA to further achieve mission.

AIICI-Associazione Italiana Cistite Interstiziale
Amador Community Foundation
American Urological Association
Astellas USA Foundation
AT&T Employee Giving Campaign
United Way
Bergman Foundation
Blythewood High School
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The Boston Club
Thrivent Financial For Lutherans Foundation
UnitedHealth Group
United States Postal Service
United Way
United eWay
UPS Foundation, Inc.
Vanguard Charitable Endowment Program
Verizon Foundation

Federal Agencies
Federal agencies also help the ICA to increase awareness about IC among healthcare providers, researchers, and the public. Special thanks to the:

Centers for Disease Control and Prevention
National Institutes of Health

Corporations
The ICA is grateful for the ongoing support we receive from our corporate sponsors, whose grant dollars enable us to offer many quality programs for the benefit of individuals with IC.

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With the advent of the new look of the ICA Update came relationships with artists living with IC and expressing themselves through a variety of mediums. Our thanks to the artists whose work appeared on the covers of the first two issues of the new ICA Update!

Kristina Hinchliff
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The thousands of members of the ICA are crucial in supporting the work we do and their gifts permit the ICA to continue to work towards improving the quality of life for people with IC. The following gifts were received for Fiscal Year Ending September 30, 2007 (October 1, 2006 to September 30, 2007).

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Susan Santone
Mary Ann Schneider
If we inadvertently omitted or misspelled your name, please let us know. Contact the ICA at ICAmail@ichelp.org or call 800-HELP ICA (800-435-7422).

If you would like to make an unrestricted gift, honor the memory of a departed loved one, make a gift in honor of someone special, or honor your healthcare provider, please send in your contribution to the ICA along with a note identifying the gift, the name of the deceased or honoree (if applicable), and the address of the individual or family who should be notified of your gift.
Ensuring Sound Fiscal Practices

In Fiscal Year Ending September 30, 2007—October 1, 2006 through September 30, 2007—the vast majority of ICA dollars (83%) was dedicated to the programs and services aimed at advocating for people with IC, as well as supporting research initiatives.

The primary source of support was drawn from the CDC Cooperative Agreement (27%). Other key sources were general donations (26%) and other restricted donations (13%).
Financial Highlights Fiscal Year Ending September 30, 2007

Statement of Financial Position
September 30, 2007

Assets

Current Assets
- Cash and Cash Equivalents $795,758
- Certificates of Deposit 107,756
- Marketable Securities 35,012
- Account Receivable 36,503
- Promises to Give 19,500
- Prepaid Expenses 24,417
- Inventory 127,083
Total Current Assets $1,146,029

Property and Equipment
- Furniture, Office Equipment, and Software 55,438
- Less Accumulated Depreciation (51,224)
  Net Property and Equipment 4,214

Other Assets
- Deposits 2,260
Total Assets $1,152,503

Liabilities and Net Assets

Current Liabilities
- Accounts Payable and Accrued Expenses $86,018
- Deferred Lease Liability 3,949
- Accrued Wages Payable 18,745
- Accrued Vacation Payable 23,728
- Payroll Taxes and Other Payables 1,547
- Deferred Revenue 2,250
Total Current Liabilities 136,237

Deferred Lease Liability 3,342
Total Liabilities 139,579

Net Assets
- Unrestricted 646,726
- Temporarily Restricted 366,198
Total Net Assets 1,012,924

Total Liabilities and Net Assets $1,152,503

Statement of Activities
For the Year Ended September 30, 2007

Support and Revenues
- General donations $485,011
- Memberships/Subscriptions 193,685
- Sale of Resource Materials 195,246
- Administrative Cost Revenue 30,100
- Research Fees 8,778
- Forums 6,125
- Combined Federal Campaign 24,747
- Research and Research Related 176,499
- Other Restricted Donations 767,479
Total Support and Revenues 1,887,670

Program Services Expenses
- Research * 249,311
- Public Health Education 199,340
- Professional Health Education and Training 388,746
- Patient Services 678,741
Total Program Services Expenses 1,516,138

Supporting Services Expenses
- General Administration 136,794
- Fund-Raising 179,527
Total Supporting Services Expenses 316,321

Total Expenses 1,832,459

Changes in Net Assets Before investment income
- Income 55,211
- Investment Income 27,174
Changes in Net Assets 82,385

Net Assets at Beginning of Year 930,539

Net Assets at End of Year $1,012,924

* As of September 30, 2007, additional research commitments of $77,588 have been made to grant recipients’ research projects. Recipients are paid one-half of grant upon signing contract and the remaining half upon completion of their research and approval of their final reports.
In 2007 we marked the retirement of longtime ICA Board member Lana Fayman. Lana gave more than 22 years of dedicated work to improve the lives of people with IC and advance the mission of the ICA. We are very grateful for Lana’s work and her support.

Achieving Mission Impact

The ICA’s Board of Directors and Medical Advisory Board members donate both their time and their talents to the ICA. Their support is essential to the ICA achieving mission impact.

Board of Directors
The ICA Board of Directors provides guidance on strategy and organizational direction. Co-chairs Minna Schrag and Marianne Schuster were key in ensuring a smooth transition during this year of change.

Co-Chairs
Minna Schrag, Esq., Partner (retired), Proskauer Rose LLP
Marianne Schuster, ICA Patient Advocate

Treasurer
Eric Zarnikow, MBA, CPA, Senior Executive, Federal Government

Board Members
Robert Evans, MD, Chief of Surgery, Moses Cone Health System
Rhonda Garrett, ICA Patient Advocate
Phyllis Greenberger, MSW, Executive Director, Society for Women’s Health Research
Blake Paterson, MD, Co-founder and CEO, Alba Therapeutics
Susan Presberg-Greene, MD, ICA Patient Advocate
F. Neal Thompson, CFP, Founder and President, Financial Services Consultants

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.

Co-Chairs
Alan Wein, MD, Chief of Urology, University of Pennsylvania Health System
Philip M. Hanno, MD, Division of Urology, University of Pennsylvania Health System

Advisory Board Members
Daniel Brookoff, MD, PhD, Center for Medical Pain Management
David A. Burks, MD, Henry Ford Hospital
Daniel B. Carr, MD, Javelin Pharmaceuticals and Tufts New England Medical Center
Toby Chai, MD, University of Maryland Medical Center
Ragi Doggweiler, MD, University of Tennessee
Robert J. Evans, MD, Moses Cone Health System
Fred Howard, MD, University of Rochester School of Medicine
David Kaufman, MD, Columbia College of Physicians & Surgeons
Susan Keay, MD, PhD, University of Maryland School of Medicine
Robert Moldwin, MD, Arthur Smith Center for Urology, Long Island Jewish Medical Center
Diane Newman, RN, MSN, University of Pennsylvania Medical Center
Christopher K. Payne, MD, Stanford University Medical Center
achieving
Honoring Vicki Ratner, MD, Founder and President Emeritus

At the AUA’s 2007 annual meeting, the association’s William P. Didusch Center for Urologic History honored women healers.

The exhibit traced the line of succession from women physicians and healers of ancient times to the first female US medical school graduate, Elizabeth Blackwell, MD, to Dr. Ratner and seven other contemporary history-making women in urology.

The AUA historians recognized Dr. Ratner as the founder and leader of the ICA as well as for her work in advising the NIH’s Interstitial Cystitis Collaborative Research Network on IC research. Because of Dr. Ratner’s efforts, noted the historians, the pathophysiology of IC is beginning to be understood and sound therapeutic approaches are being developed.

“Getting this condition that primarily affects women recognized and researched in a predominantly male medical specialty has been challenging but also rewarding,” said Dr. Ratner, who graduated from SUNY Upstate Medical University, which had its origins in Geneva Medical College, where Dr. Blackwell graduated in 1849.

Dr. Ratner’s words echo Dr. Blackwell’s, which were displayed prominently in the exhibit: “It is not easy to be a pioneer—but oh, it is fascinating! I would not trade one moment, even the worst moment, for all the riches in the world.”
The ICA does not engage in the practice of medicine. The association is not a medical authority, nor does it claim to have medical knowledge. In all cases, the ICA recommends that you consult your own physician regarding any course of treatment or medication.

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