Vision and Mission

The Interstitial Cystitis Association (ICA) advocates for research dedicated to discovery of a cure and better treatments, raises awareness, and serves as a central hub for the healthcare providers, researchers, and millions of patients who suffer with constant urinary urgency and frequency and extreme bladder pain called IC, or interstitial cystitis.

Vision
Conquering IC. Changing lives.

Mission
Early diagnosis and optimal care with dignity for people affected by IC.
Awareness among health care providers is higher.

For new patients, the time to diagnosis is considerably shorter.

Many people with IC now find viable treatment options.
And, the ICA Made it Happen

During the past year, we:

• Advocated for all those affected by IC.
• Funded research efforts and kept you abreast of research progress.
• Raised awareness about IC among patients, healthcare professionals, and the general public.

YOUR DONATION DOLLARS AT WORK

ICA Board Co-Chair Barb Zarnikow, Information Specialist Linda Salin, and Program Coordinator Anita Roach educate the multidisciplinary healthcare team at the International Pelvic Pain Society 2012 Annual Meeting. This team of IC “roving reporters” also videotaped interviews with IC experts and created plain language summaries of the scientific sessions, which are posted on the ICA’s website.
“You really helped me when I first got diagnosed.”

“I never forgot it and I remember how lonely and isolated I initially felt but you were there for me.”

“I felt like someone really listened to me and had some hope and answers.”

Susan
Advocacy is at Our Core

IC Community

• We empower and mobilize community champions.

The “Hill”

• We encourage robust federal funding for IC research and awareness.

NIH, CDC, DOD

• We track progress and identify future needs.

YOUR DONATION DOLLARS AT WORK

Neal Thompson, ICA Board of Director Treasurer and long-time IC advocate, testified in front of the U.S. Senate Appropriations Committee during the past fiscal year. Neal shared his IC story as a Virginia reservist and encouraged Congress to include IC in the scope of the Department of Defense Peer-Reviewed Medical Research Program, allowing researchers to compete for grants in their pursuit to study IC.

Through ICA advocacy efforts, IC was one of 23 conditions included on the list!
Throughout the year, the ICA monitored Congressional activities and educated leadership about IC:

- March 2012—advocates visited with Congressional offices from around the country including Alabama, Connecticut, Iowa, Maryland, Montana, Texas, Virginia, and Wyoming.
- June 2012—patients once again took to Capitol Hill and met with 24 Congressional offices representing nine states and the District of Columbia.

YOUR DONATION DOLLARS AT WORK

ICA Board Member Irma Rodriguez meets with representative Tom Price from Georgia. Her message—maintain IC biomedical research and public health funding levels.
In June, ICA Board members met with Senator Harry Reid of Nevada:

- The Senator recalled how moved he was by a group of patients he met with in the 1980’s.
- This patient advocacy visit launched Senator Reid’s more than 20 year interest in IC research and public health issues.
- ICA advocates updated the Senator on the progress gained across the last two decades and the need for continued federal funding for IC research and issues.

On behalf of the IC community, Board of Director Co-chairs Barb and Eric Zarnikow presented the Senator with an award for his years of dedication to IC research and advocacy.
The ICA provided oral and written testimony throughout the year:

- FDA Assessment of Analgesic Treatment of Chronic Pain.
- FDA Anti-Nerve Growth Factor Trials.
- NIH Committee on Research on Women’s Health.
- NIH Interagency Pain Research Coordinating Committee.
- NIH Overlapping Conditions Meeting.
- Ad Hoc Medical Research Group Meetings.
- State Pain Policy Advocacy Network.

**YOUR DONATION DOLLARS AT WORK**

At the NIH Overlapping Conditions Meeting, ICA Program Coordinator Anita Roach, ensured voices of IC patients were heard by the NIH leadership. She shared responses to a post on the ICA Facebook community page which asked, “For those with IC and other overlapping conditions: what is most important to you? Is it a clear diagnosis, better treatment options, or is it knowing the cause?”
We Put “IC” in the Federal Budget
### Advocacy Successes in FY 2012

<table>
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<th>Goal</th>
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<tr>
<td><strong>Invest in the National Institutes of Health</strong>—fund biomedical</td>
<td>fund biomedical research and continue to keep a focus on increasing IC-dedicated research at NIH aimed at finding a cause, diagnostic tool, and cure.</td>
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<td>**Include IC as a research area in the Department of Defense Peer</td>
<td>allow researchers to compete for grants in their pursuit to find better answers for all those affected by IC.</td>
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<tr>
<td>Reviewed Medical Research Program**—**allowing researchers to</td>
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<td>compete for grants in their pursuit to find better answers for all</td>
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<tr>
<td>those affected by IC.</td>
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<tr>
<td>**Fund the continuation of the Center for Disease Control and</td>
<td>the only program in the U.S. that pushes education of IC to health care providers and the general public.</td>
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<tr>
<td>Prevention (CDC) IC Education Program**—**the only program in the</td>
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<td>U.S. that pushes education of IC to health care providers and the</td>
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<td>general public.</td>
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“I so appreciate your responses and the feeling of having resources and support out there.”

“It is hard as a mother to have my child in pain and feel so helpless and far away.”

“Thank you so much for sharing and caring.”
YOUR DONATION DOLLARS AT WORK
ICA Patient Advocate Laura Santurri, MPH, CPH, served on a patient panel which helped researchers and clinical scientists to better understand the nuances of urological and pain symptoms. The NIDDK meeting on Measurement of Urinary Symptoms attendees included urologists and other clinicians, patients, researchers, industry, advocacy groups, and leadership from other government agencies. One outcome of the meeting was the release of a NIDDK grant proposal asking researchers to generate effective tools to measure differences in symptoms across subgroups of patients (phenotyping).
The ICA kept the IC community informed:

• Twelve summaries of relevant research were published the last Thursday of each month throughout FY 2012.

• Two special “roving reporter” summaries were posted from scientific meetings, including the International Society for the Study of Women’s Sexual Health and American Urological Association Meetings.

YOUR DONATION DOLLARS AT WORK

The January 2012 literature review provided plain language summaries of 16 research articles. Highlights included treatment updates on botox, cannabis, diazepam, diet, elmiron, and neuromodulation; overlapping conditions studies on endometriosis, ketamine abuse, and muscle/joint pain; genetic findings on a potential marker for Hunner’s IC and additional insights into mast cells; and a report on a fabric found to ease vulvar pain.
A key ICA survey—with your input—was published in International Urogynecology Journal:

- “Interstitial Cystitis Patients’ Use and Rating of Complementary and Alternative Medicine Therapies,” was included in the November 2012 issue.
- The article contains insights from 2,101 individuals, including 1,982 with a confirmed IC diagnosis, on complementary and alternative medicine use among IC patients.
- Our thanks to Dr. Kristene Whitmore and The Pelvic and Sexual Health Institute of Philadelphia for analyzing these results.
We Funded Research

The “Imagine No IC” Pilot Research Program helped move the field forward:

- Six research grants are currently funded on topics including epidemiology, biomarkers, alternative treatments, and biomolecular studies.
- Two multidisciplinary grant partnerships were formed during the past year—with the goal of funding additional grants:
  - American Urogynecologic Society (AUGS).
  - American Association of Nurse Practitioners.

YOUR DONATION DOLLARS AT WORK

Kristina Allen-Brady, PhD, MSPH, MPT and her colleagues from the University of Utah analyzed 15 million family history records to learn more about the genetic links of disorders such as IC and stress incontinence. Dr. Allen-Brady presented her findings at the AUGS conference and is helping practitioners better understand the challenges of IC patients—new insights gleaned as a result of ICA Pilot Research Grant funding.
We Kept Federal Funding Secure

During the past year, IC remained a priority in the portfolio of federal health agencies:

- **National Institutes of Health**: ICA met with NIDDK leadership; networked with scientists at the National Center for Complementary and Alternative Medicine (NCCAM), and participated in the Trans NIH Pain Consortium led by the NINDS.

- **Food and Drug Administration**: We testified on anti-nerve growth factor studies and IC-friendly urologist for the medical device panel.

- **Agency for Healthcare Research and Quality**: IC is included in the 2012 patient publication and clinician summary on chronic pelvic pain.
IC Advocated that IC be included the Department of Defense (DoD) Peer Reviewed Medical Research Program.

DoD named IC as area of research interest and sends out a call for proposals.

ICA encouraged leading researches to apply for this special research funding.

Dr. Michael Chancellor received a Technology Therapeutic Development Award for his IC pain research studies.
## Goal

<table>
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<tr>
<th><strong>Goal</strong></th>
<th><strong>Description</strong></th>
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<tr>
<td><strong>Fund IC research</strong></td>
<td>new ICA “Imagine no IC” Pilot Research Grant Program grants were funded and an initiative to expand interest across multidisciplinary team launched.</td>
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<tr>
<td><strong>Keep research interest in IC strong among federal health agencies</strong></td>
<td>NIH and DoD funding streams were safeguarded and grant funding awarded during this past fiscal year.</td>
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<tr>
<td><strong>Get IC research published</strong></td>
<td>Your thoughts on CAM were read by physicians around the world through original research published by the ICA in a peer reviewed journal.</td>
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<tr>
<td><strong>Monitor research</strong></td>
<td>Weekly updates kept everyone in the IC community abreast of the latest IC research activities and results.</td>
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</table>
“Thank you so much for your excellent services!

ICA provided me excellent support when I was first diagnosed, and I feel so fortunate that the service still continue.”

Debbie S
IC Education is Vital

Your donation dollars at work

In a two-page spread in the USA Today Chronic Pain supplement, the ICA spread IC awareness in the NY, Chicago, LA, and Philadelphia markets and educated 3 million readers about IC.
We Empowered Patients

ICA information and referral services were used by patients, families, friends, healthcare providers, and others. During the past fiscal year:

• Thousands of patients found the answers.
• ICA patient advocates provided individualized help, empowering patients to become self-advocates for their healthcare needs.
• Thousands of patients were connected to IC doctors who really understand IC via the ICA Healthcare Provider Registry.

YOUR DONATION DOLLARS AT WORK

Each year newly diagnosed patients contact the ICA. This year we created a special toolkit to help these women and men better understand their IC diagnosis. Facebook ads offered an inexpensive way to get the word out about this new resource!
We Served as the IC News Source

To get IC news to you quickly, we:

• Sent more than 50 eNewsletters and eblasts to over 30,000 readers on a weekly basis.
• Posted news updates and research results on the ICA website (www.ichelp.org) for the 600,000 viewers.

As the authoritative source for the media, the ICA:

• Coordinated media interviews for the lay press with ICA Board members, Medical Advisory Board members, and patient advocates.

YOUR DONATION DOLLARS AT WORK

Check out “A Girl’s Guide to Plumbing” in the November 2011 issue of the Ladies Home Journal (LHJ). Last August, the ICA reached out to the health editor of this national women’s magazine and encouraged coverage about IC in an upcoming issue. LHJ agreed. For their more than 2.5 million women readers, LHJ highlights bladder problems including IC. The ICA worked with the LHJ medical writer, fact checking the IC information included in the story.
We Got IC in the News

In national and local papers:

• We continued to get information about the need for IC research in community newspapers.
• Our team worked with the *Chicago Tribune* on a story about pelvic pain.
• In collaboration with *USA Today*, we got information about IC in a supplement about chronic pain.

On the radio:

• The ICA collaborated with the Dr. Melanie Show, setting up blog radio shows on PT, research, alternative treatments, and being a son of a dad with IC.
• ICA Patient Advocate Patty Cyr arranged for a public service announcement to air on her local National Public Radio station.
**We Kept Resources Current**

**New resources:**
- "So You Have IC, Now What?“—a toolkit for newly diagnosed patients—was launched.
- Two new ICHelp YouTube videos were posted—Amy Stein, MPT on physical therapy and Barbara Shorter, EdD, RD, CDN on IC diet.
- Three new fact sheets were created to help patients with the disability filing process.

**Updated resources:**
- Four signature brochures were updated: About Interstitial Cystitis, Sex and IC, IC and Vulvodynia, and Real Men Get IC.
- Five fact sheets were updated: Constipation, Cystoscopy with Hydrodistention, Potassium Sensitivity Test, Hydroxyzine, and Antidepressants.
- And, the ICA Restroom Access Card was revamped.
We Published Insightful Articles

Summer 2012
• Pain vs. Sleep vs. Pain
• Zapping the Pain Away
• Research Offers New Ways to Manage IC

Spring 2012
• Botox: An Injection of Hope for IC?
• Spotlight on Yoga: Risks and Benefits for Pain Management

Winter 2012
• Device Could Kill Bladder Pain
• IC Next for Cannabinoid Drug
• Trial Could Reframe IC’s Cause

Fall 2011
• Medical Marijuana, Cannabinoid Drug for IC?
• IC Alternatives, Gluten Out, IC Relief In
We Partnered Strategically

To raise public awareness, the ICA worked with key public health agencies:

- Department of Health and Human Services Office of Women’s Health—ICHelp partnered on National Women’s Health Week.
- Centers for Disease Control and Prevention—the ICA worked to help raise awareness.

To reach healthcare providers, our team:

- Sent targeted mailings to healthcare providers.
- Disseminated bulk orders of publications.
- Educated professionals at scientific meetings.

YOUR DONATION DOLLARS AT WORK

ICA Board members and staff team up at the American Urological Association’s annual meeting to educate urologists and allied health professionals on the special needs of ICA patients. The team posted daily reports of the scientific sessions and reports from the exhibit hall.
We Expanded Our Online Presence

To ensure patients get the right information about IC, we offer quality online IC information:

- **www.ichelp.org**—600,000+ viewed the daily updates provided on this comprehensive source of IC information and community news.

- **ICA Facebook Community**—10,000+ found help and support, as well as responding to ICA advocacy and research inquiries.

- **Twitter**—1,000+ follow ICA posts from scientific and advocacy gatherings.

- **YouTube**—27,800 video views and 22,000 downloads of the ICHelp interviews with experts.

- **Pinterest**—we launched a site this year, providing a peer support platform for sharing helpful resources.

**YOUR DONATION DOLLARS AT WORK**

ICHelp YouTube interviews with experts are also available for free download on the ICA iTunes store. Click on the iTunes link from the ICA website and shop for three days. The iTunes store then makes a small donation to the ICA based on your total sales!
## Education Successes in FY 2012

<table>
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<th>Goal</th>
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<tbody>
<tr>
<td><strong>Get IC in the mainstream media</strong></td>
<td>![Checkmark]</td>
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<tr>
<td>— articles about IC appeared in national magazines, national and community newspapers, broadcast and blog radio!</td>
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<tr>
<td><strong>Expand online presence</strong></td>
<td>![Checkmark]</td>
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<tr>
<td>— information about IC readily available online. The ICA worked to increase the quality of health information available via social media and launched a new Pinterest site.</td>
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<tr>
<td><strong>Provide regular updates to IC constituents</strong></td>
<td>![Checkmark]</td>
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<tr>
<td>— In addition to the quarterly ICA Update magazine, the ICA kept constituents updated via the ICA eNewsletter, eblasts, and social media posts.</td>
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<tr>
<td><strong>Leverage strategic partnerships</strong></td>
<td>![Checkmark]</td>
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<td>— we tapped into Federal health agency initiatives and also worked collaboratively with other nonprofit organizations.</td>
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"ICA is a wonderful organization."

"Excellent website!"

"Update has been very helpful."

"Use ICA Facebook and it’s been a lifesaver!"

"Great information on ICA’s podcast."
But We Are Not Finished…

In pockets of the country, access to IC experts is limited—patients continue to struggle to find knowledgeable and willing providers.

Healthcare providers are still learning about optimal treatment approaches.

There’s lots of research interest; however, understanding of the underlying cause and ultimately a cure remain beyond our reach.

THE INTERSTITIAL CYSTITIS ASSOCIATION

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