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Fiscal year 2011 brought many unexpected changes to the Interstitial Cystitis Association (ICA). It was a year of the good, the bad, and the sad.

The sad news was the loss of our beloved friend, dedicated IC advocate, and Medical Advisory Board member, Dan Brookoff, MD, PhD. At a time when many doctors doubted that IC was a real condition and were often unwilling to manage IC patients’ pain, Dr. Brookoff believed them, treated their pain, and gave them hope. He is dearly missed by many but will never be forgotten. To honor his memory, the family established the Dan Brookoff Memorial Pain Management Fund (www.ichelp.org/DanBrookoffMemorial).

The bad news was that, in spite of all our advocates’ efforts for IC awareness on Capitol Hill, continued funding for the Cooperative Agreement between the ICA and the Centers for Disease Control and Prevention’s (CDC’s) IC Program was zeroed out as of August 31, 2011. We are working to restore the funds for fiscal year 2012—more to come on those efforts.

Finally, the good news! The first-ever American Urological Association (AUA) clinical guidelines for IC are now official. They will be a huge boon, helping to end the all-too-common misdiagnosis, underdiagnosis, mistreatment, and undertreatment of IC symptoms, especially undertreatment of pain.

Also, during this past year, the ICA Board welcomed two dynamic members:

- Irma Rodriguez, who has IC herself, is a longtime supporter of the ICA. She has been a leader in professional, community, and national organizations and has been honored as a Kellogg Foundation Fellow and a Hispanic Leadership Fellow. A resident of Georgia, she recently retired from The Coca-Cola Company’s Corporate Global Office of Diversity and Workplace Fairness.

- Tony Tyler is an executive at Tyler Media, a family company that owns five radio stations, three TV stations, and an outdoor advertising division. Tony works alongside his brother Ty and his father Ralph, who has IC. Earlier this year, Tyler Media developed, sponsored, and launched an ICA public service announcement campaign, spearheaded by Tony, to reach the more than one million Hispanic people in their viewing/listening audience.

We are so very fortunate to have these new leaders on our Board and anticipate additional opportunities for the ICA in the coming year. We move into the new fiscal year with renewed vigor and determination not just to continue the mission of the ICA, but also to continue to be tenacious advocates pushing for tangible results.

Eric Zarnikow, Barb Zarnikow, and Barbara Gordon
The ICA remains true to its mission to advocate for the needs of people with interstitial cystitis, as well as those of the healthcare providers, researchers, and others who work to improve the lives of IC patients. We also empower people with IC to advocate for themselves.

Our team continued efforts to monitor federal legislation, be a presence at key public meetings, and present testimony on policy issues that impact IC care and the quality of life for those with IC. Today, tireless advocacy is required to ensure that we do not lose the momentum we have gained.

On a state level, we joined in the efforts of many pain advocacy organizations to get the word out about patients’ need for access to pain management and other healthcare services. Through our robust email list and active social media sites, we rallied IC patients, caregivers, providers, and researchers.

**Educating a New Congress**
This past fiscal year saw significant changes in Congress. The November 2010 election resulted in 94 new House Representatives and 13 new Senators. Of these, 35 Representatives had never before held elected office. The ICA and IC advocates were tasked with educating this new Congress about IC, stressing the importance of continued funding for dedicated research and awareness. The map indicates the number of states where IC patients, healthcare providers, researchers, and others heeded that call.

**INTERSTITIAL CYSTITIS ECHOES ON THE FLOOR OF THE SENATE**
In December 2010, long-term IC champion, Senate Majority Leader Harry Reid kick-started the congressional IC education process. During a discussion about the 20th Anniversary of the National Institutes of Health (NIH) Office of Research on Women's Health (ORWH) on the floor of the U.S. Senate, Reid emphasized the importance of continued funding for dedicated research and understanding of conditions such as IC. Speaking in support of a resolution proposed by Senator Barbara Mikulski to recognize the tremendous role that ORWH plays in advancing scientific research on women’s health, Senator Reid highlighted IC as an example of a condition that primarily affects women.

**ICA LEADERSHIP MEETS WITH CONGRESSIONAL LEADERS**
In February of 2011, ICA Board member Neal Thompson and Executive Director Barbara Gordon met with legislative staff in the offices of three congresspersons, Senator Barbara Mikulski, Representative Frank Wolf, and House Majority Leader Eric Cantor. Thompson, an IC patient, told his story—bringing home the message that men, too, can have IC—and provided copies of the recent *ICA Update* that focused on men and IC. Gordon shared the current prevalence figures and the need for continued research and awareness funding.

Barbara and Eric Zarnikow, ICA Board co-chairs, went local in the spring of 2011. In their home state of Illinois, the Zarnikows discussed with Jesse Jackson, Jr. the need to maintain IC research and awareness funding.

ICA reached Congressional offices in 36/50 States
“STAMP OUT IC” CONVENED IN WASHINGTON
On March 31, 2011, a record-breaking 25 patients, families, friends, healthcare providers, researchers, and ICA staffers convened in Washington, D.C. for “Stamp Out IC: Visits with Congress on Capitol Hill.” The passionate IC advocates visited 44 congressional offices representing 15 states to educate Senators, House Representatives, and their staff about the need to sustain IC research at the NIH and to continue awareness efforts through the Centers for Disease Control and Prevention (CDC).

Push for More Dedicated IC Research Funding
Throughout the past year, the ICA joined forces with other health associations to write joint letters to leaders to ensure continued funding for IC-dedicated research at NIH. This supplemented our ongoing correspondence with National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) leadership and helped keep IC in the minds of NIH research decision makers.

SENATOR REID SPEAKS WITH NIH DIRECTOR ABOUT IC
A few weeks after the Stamp Out, Gordon and volunteer Leroy Nyberg, MD, PhD, kept the momentum going in a meeting with Senator Reid, a long-time supporter for IC research and education. Senator Reid disclosed that he was scheduled to meet with NIH Director Frances Collins, MD, PhD, later that day and made a commitment to speak with Dr. Collins about the need to continue dedicated funding for IC research.

ICA BOARD CO-CHAIR, TESTIFIES AT SENATE HEARING
In June 2011, Barbara Zarnikow testified at the Senate Appropriations Committee’s Subcommittee on Defense about how IC affects military men and women and their families, thus explaining why IC should be included in the Department of Defense Peer Reviewed Medical Research Program. On behalf of IC patients, including the many veterans affected by IC, Zarnikow requested that IC continue to be eligible for this biomedical research program for fiscal year 2012.
Dignity for All Patients
Every day the ICA hears from patients about the challenges of obtaining a diagnosis and finding optimal care. Our mission includes the goal of ensuring optimal care with dignity for all those affected by IC.

WE’VE GOT GUIDELINES!
During this past year, the American Urological Association released their first-ever IC clinical treatment guidelines. These evidence-based guidelines were developed by a multidisciplinary team, including Gordon and ICA Medical Advisory Board members Phillip Hanno, MD, Christopher Payne, MD, David Burks, MD, Ursula Wesselmann, MD, and Diane Newman, RN, MSN, ANP.

The guidelines are tremendously important for the IC community because they serve as an educational tool for healthcare providers who do not know much about treating IC. The guidelines also empower patients to discuss treatment options proactively with their own healthcare providers. The AUA published the guidelines in the *Journal of Urology* and the association’s website www.auanet.org. The ICA was the first group to break the news with an interview with the team chair, Dr. Hanno, from the floor of the AUA annual meeting. Watch this two-part interview on the ICA YouTube Channel (www.youtube.com/ichielp). A plain language summary of the guidelines is also posted on the ICA website and included in the spring issue of the *ICA Update*.

Because dietary modification is included as a first-line treatment in the guidelines, Gordon, a registered dietitian and member of the American Dietetic Association (ADA), has called the ADA’s attention to the need to include registered dietitians in IC patients’ multidisciplinary team and has encouraged the ADA to push for third-party payer coverage of dietary counseling for IC patients.

GAPS IN PAIN RESEARCH, TREATMENT AND EDUCATION
In June 2011, the Institute on Medicine (IOM) released a comprehensive report on the impact of chronic pain on the 100 million American adults who have it. ICA Medical Advisory Board member Ursula Wesslemann, MD, served on the expert committee that compiled the report *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. Gordon provided public comments to the IOM as well as responses to the committee’s inquiries about the impact of IC pain.

The report highlights the need to ensure better care for people like those with IC who live with daily pain. It also highlights the need for more medical education about the needs of chronic pain sufferers. Unfortunately, the results of the landmark RAND IC Epidemiology (RICE) study that showed between 4 and 12 million people in the United States may have IC were not used in the report because the IOM report’s authors were required to use published information and the RICE study had not yet been published. Major results of the RICE study were published in the August 2011 issue of *Journal of Urology*.

ADVOCATING FOR THE SPECIAL NEEDS OF IC PATIENTS
The ICA, in collaboration with about two dozen other advocacy groups, strongly encouraged the Transportation Security Administration (TSA) to educate TSA officers on the special screening considerations for individuals with health issues such as IC. The ad hoc advocacy coalition urged TSA to develop “clear, uniformly applied policies that reasonably limit the use and scope of ‘pat downs’ for these travelers.” The ICA also continued to advocate for the safeguarding of Social Security Disability Insurance (SSDI) by:

- Monitoring the Social Security Administration (SSA) policy and regulations to safeguard IC disability rights and alerting the IC community to any changes in SSA policy and procedures.
- Developing a podcast about applying for disability benefits. The podcast is available for viewing at no charge on the ICA website and is also downloadable for free from the ICA iTunes store.
Helping Patients Advocate for Themselves

ICA and referral services continued to offer IC patients individual support in a confidential and personal environment. The association’s Information Specialists, Linda Salin and Rhonda Garrett, know from their own experiences the challenges of seeking a diagnosis and getting effective treatment for IC. Salin and Garrett, along with volunteer IC advocates, empower patients with education and information. Through the ICA Provider Registry program, they help patients find healthcare providers who treat IC. Salin and Garrett answered 10,000 emails and phone calls and distributed 35,000 resource materials.

The Voices of Hope blog, found on the ICA’s website, is filled with stories told by those with IC. The stories tell of their struggles, pain, and victories, large and small, in coping with IC. Some of our bloggers during the past year included:

- Melanie, FL: My IC Journey: In-between Potty Breaks
- Tammy, MD: Getting a Diagnosis Helped My Psyche
- Tali, NY: If You Have a Moment of Less Pain, Do Something You Love
- Teresa, MD: My Name is Teresa. Here is My Story.
- Linda, CA: Life is Good: It Can and Will Get Better
- Ed, FL: One Hundred Recommendations
- Jessica, NC: Jessica’s Story in Short Form
- Tom, CA: New Study Working For Me!
- Barb, IL: Barb’s IC Journey
- Rhonda, FL: A Personal Experience
- Lauren, KY: I Defy IC by Riding Roller Coasters
- Jennifer, MI: I Won’t Let IC Steal My Life

In its second full year, the ICA Facebook page continued to flourish. Developed as a place for those with IC to communicate and to share their struggles and successes, the Facebook page has become a wonderful resource for peer support for its more than 8,600 members. A special thanks to our Facebook monitors Salin, Garrett, Catherine Horine, and Nicki Mehall.

Partnerships Help Expand Our Reach

The ICA worked with other healthcare advocacy organizations this year, leveraging their wider networks to help accomplish mutual goals.

AD HOC MEDICAL RESEARCH GROUP

Working with this coalition of nonprofit organizations, academic medical centers, healthcare provider associations, and other medical industry leaders, the ICA advocated for robust funding of biomedical research at the National Institutes of Health.

CDC COALITION

IC is a significant public health problem. And, as the leading public health agency in the federal government, the Centers for Disease Control and Prevention has made it a goal to help patients and healthcare providers effectively manage the daily challenges of living with IC. We realized the power of partnering through this coalition, which works to safeguard CDC public health program funding.

PAIN CARE FORUM

Pain management is essential for IC patients’ optimal care and quality of life. The Pain Care Forum is a unique coalition of patient, healthcare provider, government, and industry organizations who have united to ensure access to effective treatment options for all suffering with pain.

VOICEAMERICA

Our partnership with the Dr. Melanie Show blog radio show on the VoiceAmerica Health & Wellness Channel brought experts into the homes of hundreds of IC patients and others interested in learning more. Listeners were encouraged to email or call in with questions for guest experts, including physicians, physical therapists, pain specialists, and patient advocates.
Imagine No IC Pilot Research Program
The Imagine No IC research program spurs innovation in IC research by supporting pilot projects based on promising ideas. The 26-year-old program, completely supported by private donations, has funded more than 70 projects yielding published research that significantly advanced the understanding and treatment of IC.

A study funded by the program in 2010 aimed to show what effect caffeine itself has on IC. In the controlled, randomized study using a placebo and caffeine capsules, ICA Medical Advisory Board members Robert Moldwin, MD, and Barbara Shorter, RD, EdD, found no difference between symptoms of the patients who got the real caffeine and those who got the placebo. The results were inconclusive. What was not clear to the team was whether the study subjects may have been willing to volunteer because they thought they had no problems with caffeine. So, the definitive answer to the question of whether it is caffeine or something else about coffee that sets off flares for many patients remains to be found.

Myrna Weissman, PhD, and her team from Columbia University studied the link between IC and panic disorder in certain families through genetic markers on chromosome 13. They found changes in chromosome 13, similar to those associated with panic disorders, in a subgroup of IC patients. The team noted that this offers evidence of a genetic sub-type of IC associated with panic disorder, highlighting the advantages of establishing IC phenotypes (subgroups) to better target treatments and reveal the underlying causes.

In fiscal year 2011, the ICA awarded three new research grants. Biomarkers are crucial for diagnostic tests, targeting treatments, and assessing treatments’ effectiveness. Yet, IC remains without a definitive biomarker that can be used in clinical practice. Two of the year’s awards went to researchers conducting promising biomarker research.

A third grant provided continued funding for a study already in the works:

- Tony Buffington, DVM, and his team at Ohio State University are using their grant funding to evaluate a rapid biomarker to differentiate IC from overactive bladder (OAB). Initial results on a small group of patients are promising. This test may also help doctors assess the severity of IC symptoms.

- Jayoung Kim, PhD, with Cedars-Sinai Medical Center in Los Angeles, CA, is working on understanding the mechanism of degeneration of bladder epithelial cells that occurs in IC patients and identifying biomarkers that could be used for diagnosis and evaluating treatment. Her work draws upon the existing research on antiproliferative factor (APF).

- John Warren, MD, and his team from the University of Maryland in Baltimore continued their work on the Events Preceding Interstitial Cystitis (EPIC) study. This grant period, researchers aimed to answer the following research questions:
  - Are there urogenital and systemic symptoms that predict IC?
  - What baseline factors predict improvement in IC?
  - How does quality of life change from before to after the onset of IC?
  - Is IC truly a heterogeneous condition?

Keeping IC on the Radar at the National Institutes of Health
Ongoing advocacy is essential to keep researchers focused on finding real answers. In August 2011, Gordon met with NIH IC research decision makers to
emphasize the need to continue dedicated IC programs that will fund the search for innovative solutions, such as new delivery systems to get pain medicines into the bladder. She also encouraged continuing funding of ongoing IC research even in challenging budget times.

**RAND INTERSTITIAL CYSTITIS EPIDEMIOLOGY (RICE) STUDY**

In August 2011, an article published in the *Journal of Urology*, the American Urological Association’s official publication, shared findings that the ICA had first reported in 2009. The RAND IC Epidemiology study, which surveyed 100,000 US households, found that IC is likely much more common than most experts thought, demonstrating that 3 to 6 percent of American women—3 to 8 million of them—have IC symptoms. In response to this study, the ICA adjusted its statements about IC prevalence to say that IC may affect 4 to 12 million men, women, and children in the United States.

This very large, population-based survey conveys the magnitude of IC as a public health problem and highlights its underdiagnosis. These statistics underscore the need for more research to find the cause and better treatments, for renewed effort to raise awareness, and for more widespread provider education. What’s more, these nearly established estimates spurred pharma’s interest in developing new IC therapies.

**MULTI-DISCIPLINARY APPROACH TO THE STUDY OF CHRONIC PELVIC PAIN (MAPP) RESEARCH NETWORK**

MAPP is a research network established by NIH to take an innovative approach to investigating IC. This group is studying how and why patients develop IC and how the illness changes over time. This group is also looking at genetic, behavioral/lifestyle, environmental, and other factors that may be contributors to the disease.

As a member of the MAPP Research Network Steering Committee, Gordon keeps awareness about the needs of IC patients high among NIH leadership, clinician scientists, and basic researchers. For the past three years, one of the ICA’s Medical Advisory Board members, Daniel J. Clauw, MD, has chaired this multicenter research effort. Research is being done on phenotyping IC and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) and finding the best treatment options for each phenotype.

**Reporting on the Latest Scientific and Research Findings**

During the past year, the ICA remained the go-to resource for the latest IC research findings by reporting from the floor of a number of scientific and public policy meetings, as well as providing plain language summaries of just-published studies on IC, and associated conditions.

**American Urological Association:** ICA staff attended, exhibited at, and reported from the American Urological Association’s 2011 Annual Meeting in Washington DC. More than 10,000 healthcare professionals attended, and staff educated attendees who came by the ICA booth on the latest news about and new treatments for IC. ICA’s Medical Advisory Board members Dr. Moldwin, Robert Evans, MD, and Philip Hanno, MD each taught or co-taught well-attended sessions on chronic pelvic pain.

**Society for Infection and Inflammation in Urology:** Members of the Society for Infection and Inflammation in Urology met while at the AUA. Members, researchers of the IC and chronic prostatitis/chronic pelvic pain communities.
American Urogynecologic Society: A small study (21 patients) found that 75% of patients with OAB who did not respond to anticholinergic therapy had also been diagnosed with IC. And, a pilot study (7 patients) helped confirm what many patients are learning about acupuncture and IC. Patients experienced some improvement in pain, urinary symptoms, and sexual function.

Society of Urodynamics and Female Urology: At this meeting, IC was a major focus, especially the epidemiology of IC. The meeting also provided a glimpse into what the Multidisciplinary Approach to Chronic Pelvic Pain research will yield and some new ideas about what may kick off IC and how to treat it. ICA Medical Advisory Board member Dr. Moldwin and his team at Long Island Jewish Health System reported on a survey which found that approximately 75 percent of urologists were aware of IC and comfortable treating it. A seventh of the urologists were aware of IC and didn’t feel comfortable treating it, another seventh were aware and chose not to treat IC, and almost a tenth had doubts as to whether it is a real condition or don’t believe it exists, a disappointing finding for those whose symptoms are all too real.

HEALTHCARE DEBT REVEALED
An ICA survey found that nearly 80 percent of IC patients reported carrying healthcare debt. Of those, 22 percent needed to pay off high levels of medical debt—$8,000 or more. Another quarter of people with IC are chipping away at lower levels of debt. Nevertheless, owing up to $2,000 in medical bills is daunting when you have a chronic condition that affects your ability to earn a living.

LARGEST IC AND PREGNANCY SURVEY CONDUCTED
In the spring of 2011, the ICA sponsored the largest survey ever on the topic of pregnancy and IC. The ICA will work with researchers to statistically analyze the results more thoroughly in hopes that they will spur more research and education on the subject. The article “IC and Pregnancy: Crying for Attention” with the survey results was published in the Summer 2011 issue of the ICA Update as a follow-up to the Winter 2011 special issue on pregnancy and IC, “Baby Talk: Caring for You When You’re Two.”

ICA Patient Surveys Reveal New Information
The ICA pushes IC research by regularly surveying patients and providing researchers with information about IC patient observations about the condition.

IC AND SLEEP QUALITY STUDY PUBLISHED
Results of the IC and Sleep Quality study conducted by Alis Kotler Panzera, DrNP, were published in the Journal of Urologic Nursing in the May-June 2011 issue. More than 700 patients responded to her sleep survey posted through the ICA website. Dr. Panzera and her team found that patients experienced poor sleep because of the urge to urinate frequently during the night and because of IC pain. Not surprisingly, the lack of quality sleep translated to daytime fatigue, lost productivity, depression, and an overall drop in quality of life.

HELPING BRING MORE EFFECTIVE TREATMENTS TO MARKET
Clinical trials are vital for improving treatment and quality of care for people with IC. This past year the ICA successfully helped recruit patients for a number of clinical trials. We worked with patient recruitment agencies and researchers to recruit study participants for short- and long-term clinical trials in IC, bladder pain, urgency, frequency, chronic pelvic pain, and overlapping conditions such as vulvodynia, fibromyalgia, and irritable bowel syndrome.

Gordon also alerted the heads of the U.S. Food and Drug Administration (FDA) urology committee about the special needs of IC patients for medical devices that can control IC symptoms effectively. She encouraged them to adopt a system of review that would not delay the introduction of new products to market that could offer significant relief for patients.
When you have a chronic condition like IC, you are forced to become a lifetime learner! Our goal is to arm patients, healthcare providers, caregivers, researchers, and the general public with objective and current information. Though our team is small, it is also very dedicated!

ICA News Services Bring Information and Hope
As a central information hub, the ICA works to bring the IC community the latest news in a variety of formats. The ICA Update, a quarterly, printed magazine, has become an award-winning source of news. We also host a variety of online news resources.

ICA Update
The ICA Update is one of the best reasons to join the ICA. Highlights from this past year include an issue dedicated to information for men with IC as well as an issue focusing on the subject of IC and pregnancy. An exploration of how IC affects women going through menopause and a look at pudendal nerve problems in people with IC were also covered. Interviews with top researchers in the field of IC and chronic pain, as well as healthcare providers who work day-in and day-out to help those suffering with IC, provided insight and hope. This past year more than 40,000 people benefited from the articles found in this publication.

ICA eNews
Electronic communication continued to expand this past year. The ICA eNews, an electronic newsletter, sent out twice a month to more than 30,000 readers, is filled with the latest news on emerging research, new treatments, published studies, and people in the IC community. The ICA eNews is available at no cost to anyone who signs up for it through the ICA website.

Resources Put Answers at Your Finger Tips
Getting information out there to help patients and providers make good healthcare decisions is a crucial part of the ICA mission. The ICA accomplishes that with brochures, its website, podcasts, and YouTube videos.

Brochures
This year the ICA updated the most popular topics in its brochure library. The general information brochure “About IC” was improved by incorporating the latest information on IC and improving its readability and appearance. Other updated brochures included “Real Men Get IC,” “IC and Vulvodynia,” “Sex and IC,” “Living with IC,” and “Physical Therapy May Ease IC Symptoms.”

Website—www.ichelp.org
The ICA continues to expand the site and make it easier to use. More than 40,000 users a month and 500,000 plus users a year take advantage of the vast amount of trustworthy information on the site. It is considered the “go-to” resource for patients, advocates, and healthcare providers.

Podcasts
The organization also added a number of educational podcasts to its list of resources. In 2011, the ICA created a free podcast to help IC patients who can no longer work because of their illness find their way through the complicated process of obtaining disability. The podcast is available for anyone to view on the ICA website.

YouTube Channel—www.youtube.com/ichelp
How do you differentiate yourself on YouTube? The ICHelp YouTube channel offers interviews with experts including many of the ICA Medical Advisory Board members. More than 27,000 users have learned
more about optimal care, as well as coping tips, offered by IC experts in these free videos. Links to two videos are regularly tweeted by other groups—“Treating IC with Acupuncture,” featuring Anna Kelly, MD, and “Severe IC: How to Treat It,” with Kristene Whitmore, MD.

ICA Plays Vital Role in Professional Education
The ICA educates health professionals about IC, optimal care, and the challenges of living with this life-altering bladder condition.

CONTINUING EDUCATION PROGRAM FOR NURSES
The ICA partnered with the American Nurses Association to develop the Continuing Nursing Education course “Interstitial Cystitis—chronic, common, and sometimes complicated to treat.” Published November 2010, this course is designed to help nurses identify IC, know what the newest treatments are, and support patients. The course is posted on americannursetoday.com.

EDUCATING PROVIDERS AT THEIR NATIONAL PROFESSIONAL MEETINGS
This past year the ICA also educated healthcare providers face-to-face at numerous scientific meetings and conferences:
• American Urological Association (AUA) Annual Meeting in Washington, DC
• International Pelvic Pain Society Meeting in Phoenix, AZ
• Society of Urologic Nurses Symposium in New Orleans, LA
• Society of Urologic Nurses Annual Conference in Boston, MA
• Society of Urodyamics and Female Urology, Las Vegas, NV

Awareness Activities Critical to IC Community
We often heard from patients, “How come no one has heard of IC?” But we are finding more and more that people have indeed heard of it and say they think they might know someone who has it. Although we have made progress in our quest to raise awareness, there is still much work to be done. During the past fiscal year, the ICA continued efforts to raise awareness about IC.

CDC PARTNERSHIP
For the first 11 months of the fiscal year, we continued our efforts in partnership with the CDC. Fortunately, we were able to garner some significant media coverage during this time. Funding was used to get the word out through a number of local and national media networks, help train patients how to raise awareness in their local media markets, educate healthcare providers, develop and disseminate resources, and more!

MEDIA TRAINING TRANSLATES TO COVERAGE
In March 2011, the ICA hosted a media training class for IC advocates. The goal of the class was to arm these advocates with the information and tools they would need to interact with the media successfully. Everyone who attended the class also participated in the Capitol Hill visits in Washington, DC. Of those who took the class, the following advocates followed up with action, successfully garnering media attention.

• Kristen Miles, supervisor of physical therapy at William Beaumont Hospital, was interviewed on a blog radio show about IC and pelvic floor dysfunction.
• Elisabeth Oas went on to launch a weekly internet radio blog program, The Pelvic Messenger, focused on IC and chronic pelvic pain.
• Delia Rodriguez, mother and caregiver to a daughter with a severe case of IC as well as other conditions, shared her and her daughter’s stories on The Pelvic Messenger.
• Linda Salin was interviewed by IC patient and internet radio talk show host Dr. Melanie. Linda shared her story with Barton’s 10,000 listeners.
• Dr. Shorter gave a presentation on IC to the New York Dietetic Association to help educate more registered dietitians about IC and diet.
• Tony Tyler developed a public service announcement campaign. He also shared his experience as the son of a father with IC on VoiceAmerica’s internet radio Dr. Melanie Show.

PARTNERSHIP WITH VOICEAMERICA’S DR. MELANIE
In January 2011, the ICA began a partnership with an emerging show on VoiceAmerica, an internet radio network, hosted by Melanie Barton, LCSW, MSW, EdD. Dr. Melanie, as she is called on the network, is a holistic psychotherapist with a master’s in social work and a doctorate in pastoral counseling. She also has IC.
Highlights of IC shows include:

- **January 2011**: Dr. Moldwin, an ICA Medical Advisory Board member, who discussed IC diagnosis, treatment options, and current research on IC and pelvic pain syndrome.
- **March 2011**: Medical Advisory Board member Dr. Shorter discussed how diet and nutrition affect those with IC, sharing the news that diet may not have to be as restrictive as was thought in the past.
- **April 2011**: Amy Stein, MPT, founder and practitioner with Beyond Basics Physical Therapy in New York City and author of *Heal Pelvic Pain* talked about how specialized physical therapy can help people who have IC or pelvic pain.
- **Summer 2011**: Jay Joshi, MD, an interventional pain management physician, was featured on the show to speak about managing chronic pain and to answer questions from callers.
- **August 2011**: David Burks, MD, an ICA Medical Advisory Board member, gave a review of the American Urological Association’s (AUA’s) IC treatment guidelines. And, IC patient Ed Lopatin shared his experience with IC and discussed his upcoming book, *Manage Your Chronic Illness, Your Life Depends on It*.
- **September 2011**: Amy Stein, MPT, continued to share her pearls of wisdom on the benefits of physical therapy for chronic pelvic pain. Member of the ICA Board of Directors Tony Tyler joined her and shared his family’s IC story.

**INTERNET AND SOCIAL MEDIA PRESENCE**

The ICA, in partnership with the CDC, ran an awareness campaign through WebMD. For three weeks in December and again in January, two banner announcements scrolled on pages of the WebMD website concerned with chronic pelvic pain, irritable bowel syndrome, urinary control—incontinence, fibromyalgia, and general health and wellness. The campaign secured 119,000+ impressions and more than 141 clicks and finished with a 0.12 percent click-through rate, significantly higher than the industry average of (0.06 to 0.08 percent).

Facebook ads also helped raise awareness about IC for more than 10 million social media users. The ICA developed three Facebook ads—one targeting college women, one targeting friends of people with IC, and the third targeting men. The three ads performed well during the month-long run. Overall, the Friends of IC ad resulted in the most impressions and clicks, followed by the ad for men and then the ad for college women. Together, the three ads were viewed 10,395,517 times and were clicked on 2,109 times.

During the past year, Gordon was also interviewed on two websites. She was featured in PainEDU’s “In the Spotlight” series, which offers insights from leaders working in the pain management field. She was also one of the national leaders quoted on the In Face of Pain resource center, which provides resources to empower healthcare professionals, people with pain, caregivers, and other concerned individuals to take action and advocate for appropriate and effective pain care.

Through several alliance programs on the internet, the ICA now offers awareness items for sale. The links to these sites can be found on the “Shop Now” icon on the home page of the ICA website (www.ichelp.org) where with just one click advocates can purchase a variety of items ranging from tee shirts to holiday cards.

**ICA Accomplishments Help Patients**

The ICA website, www.ichelp.org, was selected as a winner in the 13th annual Web Health Awards program, receiving a Bronze award. The ICA’s entry was chosen from more than 500 judged by a panel of experts in digital health media. This competition recognizes the nation’s best digital health resources. The Web Health Awards program is organized by the Health Information Resource Center.

The ICA was also re-certified in an independent review of the ICA website, www.ichelp.org. The Health On the Net (HON) Foundation found the site to be in full compliance with their quality standards for online medical information. The award and certification are very important to the ICA because they confirm to our ever increasing number of users that everything found on the site is completely trustworthy. The 500,000 users know they can count on the ICA!

*ICA Update* editor, Penny Allen, won the 2011 American Medical Writers Association’s (AMWA) Eric W. Martin Award for the article, “How To Talk So Your Doctor Will Listen.” This highly competitive writing award honors AMWA members who have had an article published in a reputable publication for either the public or professional audience. The article was the lead feature in the spring 2010 issue of the *ICA Update*. 
Positive Audit Report
Each year, the ICA has an independent accounting firm review our finances. This helps ensure donors, sponsors, grantors, and other contributors that we are following sound financial practices and that funding is properly used. The audit for fiscal year ending September 30, 2011, found no accounting irregularities. The ICA received a clean bill of health.

Replacing Loss of Federal Funding
A federal cooperative agreement funded through the CDC IC Program provided approximately 50 percent of the ICA’s budget. However, as a result of the fiscal 2011 federal budget cuts, the CDC eliminated this funding. The ICA was energized by the challenge of replacing the lost funds and launched some innovative ways to raise funds.

COMMUNITY FUNDRAISING TOOLKIT
In response to the many IC advocates who have expressed a desire to help through initiating fundraising activities, the ICA launched the “Imagine No IC—Let’s Pull Together Fundraiser Toolkit.” The toolkit includes the capability to develop unique, customized web pages for each fundraising activity, named for the organizer or the fundraiser, and directly linked to the ICA website. It can be found at www.ichelp.org/fundraisingtoolkit.
ALLIANCE PROGRAMS
During the past fiscal year, the ICA also partnered with several alliance programs to raise awareness and funds to keep programs offered by the ICA going. Supporters just click on the chosen icon through the ICA website to be directed to alliance partner’s site where they can purchase items. A portion of these purchases are donated to the ICA.

ICA ON ITUNES
The ICA also set up an iTunes site where people can go to download a variety of educational podcasts and audio books from top experts in the field of IC. The link to the iTunes page can be found on the ICA website. Those who click on the iTunes link from the ICA website page and purchase become instant advocates because a portion of the profit from their purchase goes to the ICA.

FINANCIAL SNAPSHOT
Most funds received were restricted to education and awareness activities. Contributions restricted to research funding were limited but enough to fund three research grants. Advocacy activities were primarily funded through general contributions.

eCARDS
The ICA line of eCards was also launched, on those special occasions—birthdays, anniversaries, holidays, and more—you can now make a donation to the ICA in honor of a friend or loved one and send her or him an accompanying eCard with a custom message.

You can now make a donation to the ICA in honor of a friend or loved one and send her or him an accompanying eCard with a custom message.
Martin Luther King, Jr. said, “The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy.” During this fiscal year, the ICA has felt those waves of struggle of setbacks—and we persevered. Our mission is clear. We must find answers for the millions who struggle with IC. We must push for better treatments. We must continue to be tenacious advocates for discovery of a cure.

**Board of Directors**

The ICA Board of Directors includes people with IC, family members, physicians, and professionals. The ICA Board guides strategic planning and organizational direction. Board members offer support for and spur interest in programs and services and provide fiduciary oversight of organizational activities. This group of volunteers dedicates time, expertise, and enthusiasm to ensuring the ICA mission is fulfilled.

- Co-Chair, Barbara Zarnikow, IC patient, public spokesperson, and active advocate
- Co-Chair, Eric Zarnikow, MBA, financial executive and husband of an IC patient
- Treasurer, F. Neal Thompson, financial services consultant and person with IC
- Holly Atkinson, MD, physician and award-winning medical journalist
- Robert J. Evans, MD, urologist who is internationally known as an expert in IC
- Phyllis E. Greenberger, MSW, Society for Women’s Health Research CEO
- Irma Rodriguez, person with IC
- Joshua A. Stein, labor and employment lawyer
- Tony Tyler, media executive and son of an IC patient
- Barbara Gordon, ex officio, ICA executive director

**Medical Advisory Board**

The ICA Medical Advisory Board provides clinical expertise on IC and chronic pelvic pain. This multidisciplinary team of urologists, gynecologists, dietitians, nurses, and basic science researchers reviews IC research grant materials, interprets guidelines and protocols, advises on communications content, and provides a link to the IC clinical, research and academic communities.

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And So Many Other Incredible Volunteers!

The work of the ICA could not be done without the help of many volunteers. We are grateful to those who helped during the last year. Thanks for your willingness to keep us on top of the latest developments, share your stories, and support all those coping with the challenges of IC.
Thanks to Our Many Donors

The work of the ICA could not be done without the generous contributions of so many. Our heartfelt thanks to all of you for the gifts that help fuel ICA education, research, and advocacy.

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