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

Each year the ICA summarizes the accomplishments of the last fiscal year in the ICA Annual Report. Thanks to the work of so many, the ICA is making a real difference. Our accomplishments include:

- Getting the word out to IC patients and healthcare providers that a multidisciplinary team of specialists is the best approach to treatment
- Acting as a voice for IC patients in the development of the first ever AUA clinical treatment guidelines
- Getting dedicated IC research in the budget of the National Institutes of Health (NIH)
- Partnering with the Centers for Disease Control and Prevention (CDC) to raise awareness
- Funding pilot research to identify biomarkers and lay the groundwork for urine tests
Much has changed for the better in the treatment of IC because of the work of the patient community and dedicated healthcare providers. There has been so much progress that the American Urological Association (AUA) announced their first-ever clinical treatment guidelines this past year.

In 2008, the AUA formed a clinical guidelines committee to develop IC treatment guidelines for urologists. Barbara Gordon, RD, our Executive Director, was honored to be an active member of this committee as a voice for people with IC. Philip Hanno, MD, chairman of the guidelines committee and co-chair of the ICA Medical Advisory Board, presented the preliminary guidelines at the AUA 2010 meeting. The emphasis in the guidelines is on early diagnosis, and multidisciplinary and multimodal treatment approaches.

ICA members helped achieve the largest survey ever conducted and analyzed of IC patients’ experiences with complementary and alternative medicine (CAM). Results of this survey were published in the *ICA Update*. The findings were also analyzed and presented collaboratively with ICA Medical Advisory Board member Kristene Whitmore, MD, Amy Rejba-Hoffmann, CRNP, and their team at the Pelvic and Sexual Health Institute and Drexel University in Philadelphia, Pennsylvania, in poster sessions at scientific meetings. In addition, the ICA, in partnership with St. Thomas Health Services in Tennessee, presented an educational seminar on multidisciplinary approaches to treating IC to a group of urologists, pain specialists, nurses, dietitians, and physical therapists in June of 2010.

*Sign from a fundraiser organized by IC advocate Lauren Snyder*
The interest in IC research has grown considerably with a new focus on translating it into practice faster. In this fiscal year, the ICA had the continuing privilege of serving on the Multidisciplinary Approach to Pelvic Pain (MAPP) Research Network Steering Committee, overseeing a five-year, multimillion dollar study funded by the National Institute of Health (NIH). Industry has also taken fresh interest in medicines for chronic pelvic pain, and the ICA worked with Pfizer on a pelvic pain assessment tool, as well as with Johnson & Johnson and Pfizer on recruitment for clinical trials. Research on isolating biomarkers funded by our organization’s pilot program and conducted by Tony Buffington, DVM, PhD, offers promise of an amino acid diagnostic marker urine test for diagnosing IC, different from APF.

To fuel interest and progress, the ICA has partnered with the Centers for Disease Control and Prevention (CDC) on a five-year program to raise awareness about IC. So far we have extended our virtual reach with a fresh face and more accessible information on our website (www.ichelp.org), created a forum for IC patients to network through Facebook, and provided access to health information for broader audiences in new formats such as video webcasts, podcasts, ICHelp YouTube channel, and tweets through Twitter. With help from some of our members, we armed support group leaders with a new tool, a LeaderKit, to assist them in offering patients needed local community support. The ICA Update, which won a National Health Information Award, brought the
Directory of Contents

Advocacy at the Government Level

Diligent Congressional Exposure

Advocacy in Action: A Doctor and a Special Needs Teacher

ICA Board Member Educates Illinois Representative, Jesse Jackson, Jr.

Strategic Alliances: Building Blocks for Better Treatment

First-Ever Clinical Guidelines for Urologists

Building Awareness in Partnership with CDC

Executive Director Chairs Committee on Acetaminophen Warning ICON

Empowering Patients

Lending a Hand to Patient Support Groups

Empowering through Knowledge: Information and Referral Services

The New Grassroots—Expanding Our Reach Virtually
ICA Serves on NIH Research Steering Committee

ICA Urges NIDDK Director to Expand IC Research Portfolio

NIDDK-funded PT Study Show Benefits for IC Patients

Association Participates in AUA Working Group

Funding Research Innovations through the IMAGINE NO IC Research Program

Surveys of Patient Trends Help Guide Research Directions

Knowledge is Power: Progress through Education

Raising Awareness with Exceptional and Timely Publications

Educating the Community

Educating Healthcare Providers

Optimizing Funds to Spur Action

Breakdown of Expenses

Financial Statement

IC Community of Advocates

Board of Directors

Medical Advisory Board

Donors

Volunteers

Staff
Prewalk activities included an inspirational speech from government affairs expert and IC patient Judi Buckalew, RN, MPH. On the morning of the Walk, Frances Ashe-Goins, Acting Director of the HHS Office for Women’s Health, spoke to the group about the importance of advocacy and praised them for their continued persistence in raising awareness for IC. Participants were also briefed by Dale Dirks and Ginger Park, of the Health and Medicine Counsel of Washington, who gave tips on best approaches at the Congressional meetings. People with IC were encouraged to share their own stories because personal stories can often be the most memorable point of the meeting for Congressional staff members. The group then broke up into teams and set out on their continuing quest to educate Congress about IC.
Advocacy in Action: A Doctor and a Special Needs Teacher

The ICA continued to educate Congress and other leaders on the need for additional federal research funding and a sustained focus on finding more effective treatments for IC. In May of 2010, ICA staff member Barbara Gordon, and volunteer Dr. Lee Nyberg, joined Congresswoman Nita Lowey (NY) for an informal breakfast. The message: Please urge NIDDK to continue to fund dedicated IC projects and foster interest about IC among young researchers.

Lauren Snyder, a 29-year-old special needs teacher from New Jersey, submitted written testimony to the Congressional Defense Appropriations Subcommittee on IC. Lauren encouraged dedicated IC funding in the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP), noting that this program is an indispensable resource for studying emerging areas in IC research, such as prevalence in men, the role of environmental conditions such as diet in IC development and diagnosis, barriers to treatment, and IC awareness within the medical military community.

As a testament to the power of Lauren’s story and other advocacy efforts of the ICA:

- The ICA was asked to nominate an IC patient to participate in review of the PRMRP grant proposals—and the ICA’s nominee, Judi Buckalew, was selected. Judi served on multiple committees, offering her unique insights as a patient with a chronic condition to the grant award decision-making process.

- Meredith Robbins, PhD, a visceral pain researcher with the University of Alabama at Birmingham, received grant funding from the DoD PRMRP to study IC pain.

ICA Board Member Educates Illinois Representative, Jesse Jackson, Jr.

Barbara Zarnikow, long-time IC advocate and co-chair of the ICA Board of Directors, attended a birthday celebration for Jesse Jackson, Jr. on March 19, 2010 in Chicago, Illinois. After wishing Representative Jackson a happy 45th birthday, Barbara took the opportunity to discuss the special needs of IC patients with him, highlighting the need to continue to raise awareness about IC by sponsoring outreach activities targeting healthcare providers and people with IC.

The ICA has practiced these government-focused advocacy and education activities since its inception. As we learn new information about the prevalence and severity of IC in this country, the ICA makes sure our country’s leaders are informed so they can make educated decisions about IC-dedicated funding and research.
The AUA released the preliminary version of its first-ever IC clinical guidelines. On behalf of the AUA's IC guidelines committee, Dr. Philip Hanno, who is also co-chair of the ICA Medical Advisory Board, presented the preliminary guidelines for diagnosis and treatment from the association at the AUA's 2010 annual meeting in May. Representing the ICA, Barbara Gordon has served as an active patient advocate on this guidelines committee since its inception.

The guidelines emphasize conservative, noninvasive approaches to start, such as an IC-friendly diet, physical therapy aimed at pelvic floor dysfunction, and stress management. Therapies called first-line treatments include certain oral medicines and bladder instillation therapy. The guidelines recommend that if these are not effective, to then step up slowly to stronger or more invasive treatments as needed. Dr. Hanno pointed out that the guidelines emphasize the need to address pain at every level of treatment.

He also stressed that these guidelines are a work in progress and far from the final word on IC diagnosis and treatment. The guidelines reflect what has been published so far in controlled trials or other trustworthy studies and sometimes on expert opinion, so they don't necessarily include helpful treatments that IC experts are just starting to research and use. Nevertheless, these guidelines are a huge milestone in the fight for raising awareness and providing better treatment to patients.
Building Awareness in Partnership with CDC

Working in collaboration with the Centers for Disease Control and Prevention, the ICA continued to develop and implement vital programs to enhance public awareness and healthcare provider knowledge regarding IC.

This fiscal year marked the final year of a five year grant with the CDC. The primary goal was to create a more robust online presence, as the ICA worked to make it easier for people with IC to find authoritative information about the disease. To combat misinformation on the web, the ICA and CDC leveraged social media tools to raise awareness among healthcare providers and the public:

- ICHelp YouTube Channel—features interviews with experts
- ICHelp on Twitter—provides real-time tweets from scientific meetings
- eNews—gets timely updates out to constituents about happenings in the field and tips on coping with IC

Transition of the ICHelp website to a web 2.0 platform allowed the ICA to offer improved interaction among those with IC, their families, advocates, healthcare providers, researchers and public health scientists. With this transition, the ICA also launched the “Voices of Hope” blog for patients to share inspiring stories as well as the ICA Facebook community which provides an online, peer-to-peer support network.

This ICA/CDC partnership also allowed for continued public awareness through regional public forums. In addition to in-person meeting formats, forums went virtual as webinars and as a live, interactive webcast.

The ICA used a multi-pronged approach to educate healthcare professionals about IC, including: (1) Forming strategic partnerships with healthcare professional organizations and co-hosting continuing medical education programs, (2) collecting data on patient trends and presenting the findings at key medical conferences, (3) co-authoring an article for the peer-reviewed literature about IC pain management, and (4) staffing exhibit hall booths and interacting one-on-one with providers about IC and the special needs of IC patients.

By optimizing a variety of channels and strengthening the virtual reach, the ICA and CDC reached hundreds of thousands of patients and healthcare professionals.

Executive Director Chairs Committee on Acetaminophen Warning Icon

Many IC patients rely on acetaminophen to control their IC symptoms. After the US Food and Drug Administration (FDA) issued consumer warnings about the maximum recommended dose of the pain medicine, Barbara Gordon chaired a subcommittee of the Pain Care Forum Acetaminophen Task Force to evaluate the feasibility of creating an icon for medicines containing acetaminophen.

This team of industry and nonprofit patient and healthcare provider organizations developed and administered a feasibility survey about an acetaminophen icon concept. Results were presented at the scientific meeting Advancing Our Understanding of the Safe Use of Acetaminophen on November 10, 2010, in Bethesda, Maryland.
Lending a Hand to Patient Support Groups

As a part of its ongoing grassroots efforts to provide patients with tools they can use to help themselves, the ICA developed a Support Group LeaderKit for those interested in starting a support group in their area. It was developed by an ad hoc committee of ICA patient advocates, many of whom are present or past support group leaders, and chaired by Lauren Snyder, one of the voices of young IC patients.

Committee members collected feedback from their grassroots network about key topics and specific tools to include in the LeaderKit. The tools incorporated into the LeaderKit have been proven to empower support group leaders and participants. The LeaderKit is available on the ICA website.

In addition, the ICA website provides a listing of established local and regional support groups throughout the country, and the website and eNews carry notices of their meetings.

Empowering through Knowledge: Information, Referral, and Networking Services

The ICA continued its distinctly personal touch of answering calls and inquiries from patients and healthcare professionals. Linda Salin, ICA Information Specialist, and volunteer IC advocates helped empower patients to find the providers they needed and to take control of their healthcare. Patients were also connected to other patients for peer support through the ICA national network of patient advocates, which include both English and Spanish speakers.

With the economic downturn in our country, the ICA saw an increase in public inquiries about the disability process and how to apply for disability benefits from their employer and the Social Security Administration. To meet this need, the ICA created a podcast reviewing short-term, long-term, and Social Security disability benefits. It was launched on the ICA website for free viewing in early 2011.

The ICA Healthcare Provider Registry, a list of clinicians who agree to be a referral source for IC patients, continued to grow.

A variety of specialized informational brochures and fact sheets with topics such as men and IC, diet, and sexuality were available for order online for individuals or in bulk for healthcare providers and educators.
The New Grassroots—Expanding Our Reach Virtually

The ICA revamped its website, www.ichelp.org, to make it more dynamic, user-friendly, and content rich. The organization added new materials and tools including a blog, “Voices of Hope”, focused on sharing the stories of people with IC. Nearly 40,000 users visited the site each month (approximately 500,000 users in a year) to learn about the latest IC treatments and research.

In 2010, the ICA created and began hosting an interactive online networking and support site for IC patients and their families through Facebook. This patient support forum is moderated by ICA staff and ICA patient advocates, and serves as a resource where people can find information, seek advice, share their stories, and talk to others affected by IC. More than 5,400 members participate in ongoing discussions.

The IC Help YouTube channel offers interviews with the experts. In May of 2010, Penny Allen, ICA Communications Manager, broke the story of the first-ever AUA IC treatment guidelines as it was announced and posted an interview with the chairman of the guidelines committee from the floor of the AUA convention.

Real-time news and informational messages are broadcast through Twitter, www.twitter.com/ICHelp, from medical meetings and as news breaks about IC research.

The concept for a series of podcasts was developed to cover a variety of topics that the IC community has indicated are important and sometimes difficult to understand. The first one, A Guide to the Healthcare System, was written especially for the newly diagnosed or not yet diagnosed IC patient and narrated by Linda Salin. It was posted online in 2010 with additional podcasts planned for 2011.

“My greatest thanks go to you and ICA for all the help we receive so quickly. You have no idea what peace of mind I have knowing you are available to help us.”

– Shirley
ICA Serves on NIH Research Network Steering Committee

Barbara Gordon continued to serve on the MAPP Research Network Steering Committee. This five-year, $37 million, ground-breaking, multisite, NIH-sponsored research program is yielding a broader approach to the study of IC in men and women, and chronic prostatitis/chronic pelvic pain syndrome (CP/CPPS) in men.

Barbara provided input into the design of study protocols, helping researchers to gather data about IC symptoms without imposing a burden on the typical IC patient. She also participated in working group discussions regarding patient recruitment strategies.

ICA Urges NIDDK Director to Expand IC Research Portfolio

Two members of the ICA team, Barbara Gordon, and Medical Advisory Board member Daniel Brookoff, MD, PhD, met with Griffin Rodgers, MD, the director of NIDDK. Barbara and Dr. Brookoff discussed the current NIH IC research portfolio with Dr. Rodgers and his senior leadership team of scientists and physician researchers. NIDDK reported on the status of research grants funded by the federal government, including newly awarded American Recovery and Reinvestment Act (ARRA) funds.

NIDDK-funded Physical Therapy Study Show Benefits for IC Patients

Pelvic floor-directed physical therapy for IC symptoms has become increasingly popular, but the scientific backing was lacking. Past ICA advocacy efforts yielded the NIDDK-funded, randomized, controlled, multicenter study on pelvic floor physical therapy. During the past year, results showed the benefit of manual physical therapies in the treatment of chronic pelvic pain. Sixty-nine percent of women patients responded to physical therapy, significantly more than the 26 percent of the massage-only controls. That showed the effect is real—and strong—for women with IC.

Association Participates in AUA Working Group

The ICA was at the American Urological Association (AUA) Research Summit on Pelvic Pain working group. At the summit, ICA staff educated researchers, clinicians, industry representatives, and other nonprofit leaders...
about IC. As a voice for IC patients, the ICA played a major role in identifying the gaps in IC research and drafting the recommendations for key research areas for IC and chronic pelvic pain conditions.

**Funding Research Innovations through the IMAGINE NO IC Research Program**

Often investigators with novel IC research ideas cannot get funding from NIH because they lack preliminary data. To help them overcome that obstacle, the ICA founded the ICA Pilot Research Program in 1985. Twenty-five years later, this modest pilot program has funded over 70 projects, totaling more than $1 million and resulting in key advancements. It still remains the first and only IC dedicated research program funded by a nonprofit patient association.

In this fiscal year, the ICA Pilot Research Program, with funds raised from our IMAGINE NO IC campaign, continued to provide researchers with the vital initial funding they need to get their projects off the ground and give people affected by IC hope that there will soon be a world free of IC. Funded solely by private contributions, largely from ICA members, the ICA Pilot Research Program opens the door for researchers, enabling them to demonstrate research results that can bring large government grants to further explore the causes and treatments of IC.

Grant awards that began in fiscal year ending 2010 include:

- **The Effects of Caffeine on the Symptoms of Interstitial Cystitis/Painful Bladder Syndrome**
  Robert Moldwin, MD, Smith Institute for Urology, NY

- **A Medical Syndrome Involving Interstitial Cystitis Linked to Chromosome 13**
  Myrna M. Weissman, PhD, Division of Epidemiology, Columbia University

**Surveys of Patient Trends Help Guide Research Direction**

More than 2,100 people responded to the ICA’s 2009 Complementary and Alternative Medicine (CAM) Survey, a larger response than almost any other survey of IC patients. The survey showed that two CAM therapies have made it into mainstream medicine—diet and physical therapy—tried by 81 percent of the respondents. Mind-body approaches such as stress reduction and relaxation techniques were also found to be effective for many. Preliminary findings of the study were first published in the Summer 2009 ICA Update.

The results were so significant that further statistical analysis of the data was done in collaboration with Amy Rejba-Hoffmann, CRNP and ICA Medical Advisory Board member Kristene Whitmore, MD, both with the Pelvic and Sexual Health Institute in Philadelphia, and presented at key scientific meetings.

Over 917 IC patients participated in another ICA online survey concerning exercise practices. A staggering 73 percent of patients reported that they exercise, and just over half reported trying to exercise more than a couple of times per week. National studies show 30 percent of Americans get little or no exercise, so this was an impressive finding and way ahead of the curve. The findings from the survey prompted Pfizer to develop a new IC assessment tool that includes a question about exercise.
Over the years, the ICA has become known as one of the most authoritative sources of information and education about IC.

**Raising Awareness with Exceptional and Timely Publications**

The ICA beefed up its communications program with a new level of excellence in its existing publications and a new electronic newsletter.

**ICA eNews** — To meet the growing demand for delivering IC news in real time, the ICA launched its eNews to replace the monthly Café ICA. The eNews went out to 20,000 loyal readers, and additional users visited this section of the website to access the latest IC news and research findings. Readers received regular advice on diet, reader-friendly summaries of the latest published research, breaking health news, and timely tips.

**ICA Update** — The ICA’s quarterly, full color magazine was recognized for excellence, receiving the National Health Information Award for its special 2009 issue that focused on self-help, with empowering articles on doing bladder instillations at home, making a difference with diet, improving sleep, rekindling sexuality, and exercising.

Incorporating outstanding photography and art from patients and professionals in striking layouts, the publication brought patients, healthcare providers and researchers fresh information about treatment and daily living from top experts in widely disparate fields—pain management, healthcare communication, the arts, and cooking. The magazine established a new column, IC Alternatives, responding to the IC community’s demand for information about CAM therapies. The ICA distributed approximately 40,000 copies of the ICA Update in fiscal 2010 to members, medical practices, support groups, partnering organizations, and healthcare professionals attending scientific meetings.

**Professional Perspectives** — Written for medical providers and containing the latest information on research, treatments, news, and events, this publication was distributed free of charge to thousands of healthcare professionals to educate and inspire greater interest in the treatment of IC.
Major radio, television and print media picked up news about the ICA, IC research, and treatment. Of note during the past year was the appearance of ICA Medical Advisory Board member, Kristene Whitmore, MD, on The Dr. Oz Show. Dr. Whitmore helped viewers better understand the challenges of diagnosing IC. Syndicated columnist Paul Donohue, MD, also helped get the word out by featuring multiple columns about IC in local newspapers around the country.

Through its work with the Google Grant’s AdWords program, the ICA released several online promotions in 2010 to increase awareness of IC by driving patients and medical providers to key areas of the ICA website.

**Educating the Community**

More than 65 patients and family members gathered in Nashville, Tennessee, for the Finding Better Relief patient forum on June 5, 2010. Barry Jarnagin, MD, and Ragi Doggweiler, MD, spoke of how they bring together the latest treatments and techniques from urology, gynecology, gastroenterology, and alternative medicine to help people with IC get better.

For participants who could not travel to the forum because of the distance, or because their severe pelvic pain or urinary urgency and frequency prevented them from traveling, we brought the seminar to them live with a streaming webcast. The webcast drew 81 people from 31 states and 3 countries.

“The video link you provided was invaluable to me right now, and I took notes like a madwoman. I wish I had found you all a couple years ago!”

– Brenda
Speakers responded to questions during the forum, and then followed up with written responses to the questions they had not been able to answer during their presentation. A document with all questions and answers was posted online. A free recording of the webcast continues to be available on the ICHelp YouTube channel.

The ICA also revamped its website, www.ichelp.org, to make it more dynamic, user-friendly, and content rich. The organization added new materials and tools including a blog, “Voices of Hope”, focused on sharing the stories of IC patients and an IC Awareness Tool Kit—Dare to be ICAware. Nearly 40,000 users visited the site each month (approximately 500,000 users each year) to learn about the latest IC treatments and research.

**Educating Healthcare Providers**

The ICA provided one-on-one healthcare provider education at a number of scientific meetings and conferences:

- American Academy of Pain Management Clinical Conference
- American Dietetic Association Annual Meeting
- American Urological Association Annual Meeting
- American Public Health Association Meeting
- American Academy of Pain Management Annual Meeting
- Society for Urodynamics and Female Urology International Continence Society/International Urogynecological Association 2010 Joint Annual Meeting
- Society of Urologic Nurses and Associates Annual Conference
At all of these conferences, ICA staff also spoke to providers at the exhibit booth and supplied them with valuable resources to help them understand the needs of IC patients as well as news of the latest treatments. We reported on these conferences, broadcasting real-time information about research findings and new treatments directly to patients via Twitter/IC Help and posted live interviews on the IC Help YouTube channel.

Urologists, urogynecologists, and pain practitioners learned how and which CAM therapies helped IC patients when the analysis of the ICA’s robust Complementary and Alternative Medicine Survey was presented at scientific meetings. The analysis was summarized on a poster, displayed and discussed at the:

- International Continence Society/International Urogynecological Association 2010 Joint Annual Meeting in Toronto in October.

ICA Medical Advisory Board members Drs. Phillip Hanno, Alan Wein, Robert Moldwin, Kristen Whitmore, Christopher Payne, Deborah Erickson, and Robert Evans educated healthcare providers through numerous presentations about new treatments and clinical guidelines for IC patients at the Annual Meeting of the American Urological Association (AUA). The CME program for physicians, A Multidisciplinary Approach to Pelvic Pain, preceded the Finding Better Relief patient forum in Nashville, Tennessee. Barry Jarnagin, MD, director of the Center for Pelvic Health at Saint Thomas Health Services in Franklin and Nashville, and others on his team discussed their innovative multidisciplinary practices to address all the health issues those with IC face.

To help pain practitioners understand more about treating IC, ICA Medical Advisory Board member Robert Moldwin, MD, ICA Update editor Penny Allen, and Barbara Gordon wrote the article “Pain Practitioners: Critical Partners in Interstitial Cystitis Care” for The Pain Practitioner, which is published by the American Academy of Pain Management. The article, which appeared in the Spring 2010 edition, helped pain practitioners understand what IC is and what treatments they can offer and manage for IC patients.

I just read your treatment overview in the latest edition and I am writing to thank you. I learned so much! You really brightened my day and gave me lots of ideas. THANKS!

– KF
Breakdown of Expenses

During this year, the ICA responded to the tightening of the economy and the call to be a good steward of donations by streamlining operations, which reduced costs and optimized the donation dollars so vital to our work.

The following is a summary of the financial statements incorporated in the annual audit report issued by Councilor, Buchanan & Mitchell, P.C. for the year ended September 30, 2010. The complete financial statements and notes are available to view on ICA’s website www.ichelp.org located in the About ICA section.
### Statement of Activities - For the Year Ended September 30, 2010

<table>
<thead>
<tr>
<th>SUPPORT AND REVENUES</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grants</td>
<td>$639,062</td>
</tr>
<tr>
<td>Donations</td>
<td>$477,074</td>
</tr>
<tr>
<td>Sales of Resource Materials</td>
<td>$119,022</td>
</tr>
<tr>
<td>Miscellaneous Income</td>
<td>$3,455</td>
</tr>
<tr>
<td><strong>Total Support and Revenues</strong></td>
<td><strong>$1,238,613</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EXPENSES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PROGRAM SERVICES EXPENSES</strong></td>
</tr>
<tr>
<td>Research</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>Advocacy</td>
</tr>
<tr>
<td><strong>Total Program Services</strong></td>
</tr>
</tbody>
</table>

| **SUPPORTING SERVICES EXPENSES** |
| General Administration | $47,416 |
| Fund-Raising           | $94,170 |
| **Total Supporting Services** | **$141,586** |
| **Total Expenses**     | **$1,136,076** |

**Changes in Net Assets**
- Before Investment Income | $102,537 |
- Investment Income       | $5,303 |
**Changes in Net Assets** | **$107,840** |
**Net Assets at Beginning of Year** | **$865,790** |
**Net Assets at End of Year** | **$973,630** |
Board of Directors

Interstitial Cystitis Association Board of Directors includes people with interstitial cystitis, family members, physicians, and professionals. The 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 their time, expertise, and enthusiasm to ensuring ICA mission fulfillment.

Barbara Zarnikow, Co-Chair
Special Education Teacher (retired) and ICA Patient Advocate

F. Neal Thompson, Treasurer
Founder and President of Financial Services Consultants

Holly Atkinson, MD, FACP
Chief Medical Officer and Senior Medical Correspondent for HealthiNation

Robert J. Evans, MD
Associate Professor of Urology at Wake Forest University Baptist Medical Center

Rhonda Garrett, MA
ICA Patient Advocate

Phyllis E. Greenberger, MSW
President and CEO of the Society for Women’s Health Research

Barbara Zarnikow, Co-Chair

Eric Zarnikow, MBA, CPA Co-Chair
Management Consultant

Joshua A. Stein
Co-head of Accessibility & Accommodations Group for Proskauer Rose LLP

Paula Whelan
ICA Patient Advocate
The Interstitial Cystitis Association Medical Advisory Board provides clinical expertise on interstitial cystitis/painful bladder syndrome, and chronic pelvic pain. This multidisciplinary team of urologists, gynecologists, dietitians, nurses, and basic science researchers volunteer their time to review IC research grant materials, interpret guidelines and protocols, and provide a link to the IC clinical, research and academic communities.

Daniel Brookoff, MD, PhD
Consultant

David A. Burks, MD
Private Practitioner

Daniel B. Carr, MD
Javelin Pharmaceuticals, President and CMO and Tufts New England Medical Center, Professor of Anesthesiology and Medicine

Daniel Clauw, MD
Director, Chronic Pain and Fatigue Research Center at the University of Michigan

Ragi Doggweiler, MD
Associate Professor of Urology, University of Tennessee

Robert J. Evans, MD
Associate Professor, Urology, Wake Forest University

Fred Howard, MD
Director of the Division of Gynecologic Specialties, University of Rochester School of Medicine

David Kaufman, MD
Assistant Professor, Clinical Urology, Columbia College of Physicians & Surgeons

Susan Keay, MD, PhD
Professor of Medicine, Division of Infectious Diseases, University of Maryland School of Medicine

Robert Moldwin, MD
Physician in Charge of Urologic Infectious/Inflammatory Diseases, Smith Institute for Urology and Long Island Jewish Medical Center

Alan Wein, MD, Co-Chair
Chief of Urology, University of Pennsylvania Health System

Philip M. Hanno, MD, Co-Chair
Division of Urology, University of Pennsylvania Health System

Diane Newman, RN, MSN
Director for Continence and Health and Instructor, University of Pennsylvania Medical Center

Christopher K. Payne, MD
Associate Professor, Urology, Stanford University Medical Center

Barbara Shorter, RD, CDN, EdD
Associate Professor of Dietetics, Department of Nutrition, Long Island University

John W. Warren, MD
Professor of Medicine, Division of Infectious Diseases, University of Maryland School of Medicine

Ursula Wesselmann, MD, PhD
Professor, Department of Anesthesiology, University of Alabama at Birmingham

Kristene E. Whitmore, MD
Professor and Chair of Urology, Drexel University College of Medicine

Monica Liebert, PhD, Special Consultant
Professor, Department of Urology, University of Michigan, Ann Arbor, MI

Chris Mullins, PhD, NIDDK Liaison
Director, Basic Cell Biology Program, NIDDK, NIH
The work of the ICA is made possible solely through the generosity and vision of individuals, foundations and corporations. Donations are used to keep programs and services operating at peak strength so that every IC patient who needs help can find it through the ICA. Gifts received in fiscal year October 1, 2009—September 30, 2010 are as follows:

**Foundations & Giving Partnerships**

Amador Community Foundation
Amazon Services
AT&T United Way Employee Giving Campaign
Boeing Charitable Trust
Briggs Foundation
Carmax Foundation Matching Gifts Program
Chemsultants International Inc.
Chevron Humankind Matching Gift Program
Employees Community Fund of the Boeing Company
firstgiving
GE Foundation Matching Gifts Program
Hannah Foundation
Illinois Tool Works Foundation
Karen and Christopher Payne Family Foundation
Merck Partnership for Giving
Morgan Stanley Smith Barney
Global Impact Funding
Trust Inc
Oklahoma City Community Foundation
Pfizer Foundation Matching Gifts Program
PIMCO Foundation
Prudential Foundation
The Charlesmead Foundation
The Foundation For The Jewish Community
The Fred R. Fernandez & Irma R. Rodriguez Foundation, Inc.
The Luckens/McAdams Foundation
The Prudential Foundation Matching Gifts
The Samuel and Rebecca Kardon Foundation
Stellar Solutions Foundation
The T. Rowe Price Program For Charitable Giving
Vanguard Charitable Endowment Program
Trust (formerly United Way of Tri-State & United eWay)

**Corporate Sponsors & Grantors**

AkPharma Inc.
Alwen Consumer Healthcare, Inc.
Bayer Healthcare
BKK Sports LLC
Clark Construction Group, LLC
Desert Harvest, Inc.
Endo Pharmaceuticals
Green Mountain Coffee Roasters
Integrated Communications Corporation
MediciGroup, Inc.
Ortho-McNeil-Janssen Pharmaceuticals
Pfizer, Inc.
Prime Life Fibers Inc.
PROTOTYPE Ltd.
Purdue Pharma L.P.
Taiho Pharmaceutical Co., Ltd.

**Major Individual Contributors**

**Gifts of $10,000 or Greater**

Daniel & Susan Guggenheim
Lisa Schwartzberg
Barbara and Eric Zarnikow

**Gifts of $5,000 to $9999**

Diane Brown
Denis Castenfelt
Mary & Bruce Donald
Gerry and Jackie Kaminsky
Suzanne Kitzman
Kristene Whitmore, M.D.

**Gifts of $1000 to $4999**

Dorothy Banner
Terese Beam, MD
Bianca Bellesi
Jean & Jim Boak
Michael Chancellor, M.D.
Ragi Doggweiler, M.D.
Gregg Dwyer
Robert Evans, M.D.
Cynthia Fineman, M.D. & Gary Fineman
Don & Elzina Forbes
Brigid Fejes
Barbara Gordon
Susan Prezberg-Greene, M.D. and Robert Greene, M.D.
Virginia Gross
Matt Hazzard
Marjorie H. Hohe
Susan Key, M.D., Ph.D.
Eleanor Kilberger
Rev. Dwayne Knight & Fern Knight
Marguerite Landry
John & Colleen Lohrer
Veda “Mickie” Mearns
Nancy Morgan
Hugh Northcutt, M.D. & Melanie Northcutt
Sidney & Phyllis Rodbell
Phyllis Schwartz
Audra Scully, M.D.
Brent Terry
F. Neal Thompson, CFP
John Verdon, Jr., M.D.

**Gifts of $500 to $999**

Catherine Beckley
Sara Bershel
L. Bishop
Brenda Black
Susan Brown
Gail C. Bunes
Susan Carson
Janet Carter
Anne Cheng
Cynthia DeBoard
Martha DePrisco
Joan Dietz
Claire Doucette
Diana Dunn, Ph.D.
Robert F. Graves, M.D.
Stephen Grether
Patricia B. Hansch
Laura Hawkins
Karen Jackson
Glendena Joyce
Kaye Kreuzfeldt
Carolyn Lawrence
Eliza Lear
Vivian Zeik Leonard
Laura Leprino
Judy Lipham
Wendy Lyons
Robert Mayer, M.D.
Derek Meisner
Nancy Meller
Donna Montosa
Sheila Moore
Jane Nadelson
Nicole Panzarella
William Perry
Timothy & Elaine Peterson
Lana Powers
Sharon Powers
Jo Anne Pullen, M.D.
Eugenie Rehak
Martha Rosenblatt
Sharon Rubin
Risha & Paul Samuelson
Pamela Savarese
Hazel Schlosser
Minna Schrag
Marillyn Schreibstein
Jeanne Scott
Laurie Sheffield
JoAnn E. Vierthaler
Carolyn West
Paula Whelan
Nancy Williams
Mr. & Mrs. Frank Vetter
Naoki Yoshimura, M.D. & Tomoko Yoshimura

**Gifts of $250 to $499**

Dr. & Mrs. Ronald Armengol
Janice Barlowski
Linda Beckman
Judith Beier
Cynthia Bismayer
Jeffrey Borowski
Nancy Bozeman
Lilian Camio
Mary C. Caputo
Diana Carlson
Don Cassedy
Patricia L. Cofer
Elizabeth Craig
Brenda Czerwik
Gregory Davis, MD
Doreen DeBliek
Raymond Duvall
Mildred Demey
Pamela Flukey
Betsy Gardner
Carol Gold
Norma Goth
Ellen Haas
Arlene Haemmerle
Paul & Marilyn Halvor
Charles Kastigar
Sadie Kestner
Cindi Krebs
Jack Larabee
Frank Madden
Teresa McCoy
Mildred Demey
Anna Molloy
Jill Murrow
Lisa Myers
Peggy Norman
Ginny O’Keefe
Lorraine Olzowski
Susan Oxman
Claribel Parker
Faye Parsons
Kenneth Paylor
Evelyn Pazik
Helen Sue Price
Thelma Presnell
Susan Prestera
Arline Ravitch
Jamie Rulon
Linda R. Salin

**Gifts of $50 to $999**

Marguerite Landry
Rev. Dwayne Knight & Fern Knight
Marguerite Landry
John & Colleen Lohrer
Veda “Mickie” Mearns
Nancy Morgan
Hugh Northcutt, M.D. & Melanie Northcutt
Sidney & Phyllis Rodbell
Phyllis Schwartz
Audra Scully, M.D.
Brent Terry
F. Neal Thompson, CFP
John Verdon, Jr., M.D.

**Gifts of $100 to $499**

Sarah Bershel
L. Bishop
Brenda Black
Susan Brown
Gail C. Bunes
Susan Carson
Janet Carter
Anne Cheng
Cynthia DeBoard
Martha DePrisco
Joan Dietz
Claire Doucette
Diana Dunn, Ph.D.
Robert F. Graves, M.D.
Stephen Grether
Patricia B. Hansch
Laura Hawkins
Karen Jackson
Glendena Joyce
Kaye Kreuzfeldt
Carolyn Lawrence
Eliza Lear
Vivian Zeik Leonard
Laura Leprino
Judy Lipham
Wendy Lyons
Robert Mayer, M.D.
Derek Meisner
Nancy Meller
Donna Montosa
Sheila Moore
Jane Nadelson
Nicole Panzarella
William Perry
Timothy & Elaine Peterson
Lana Powers
Sharon Powers
Jo Anne Pullen, M.D.
Eugenie Rehak
Martha Rosenblatt
Sharon Rubin
Risha & Paul Samuelson
Pamela Savarese
Hazel Schlosser
Minna Schrag
Marillyn Schreibstein
Jeanne Scott
Laurie Sheffield
JoAnn E. Vierthaler
Carolyn West
Paula Whelan
Nancy Williams
Mr. & Mrs. Frank Vetter
Naoki Yoshimura, M.D. & Tomoko Yoshimura
Deborah Schwartz-Kates, Ph.D.
Martin Stern, M.D. & Kathy Stern
Sue Stiller
Barbara Thomason, PhD
Constance Twomey
Susan R. Vincent
Leesa White
DeLana Wicker
Donna Williams
Julia Wilson
Diane Zentmyer
Fran Zupan

Gifts of $100 to $249

Jeannine Abdalla
Gayle Ackley
Arturo Alba
Stella Alex
Judith Allen
Patricia Amman
Eleanor Anastasio
Jo Ann Anderson
Ann Angileri
Margaret Anteau
Stanley Antolak, Jr., M.D.
Suzanne Appelbaum
Diane Appelman
Ronald & Christine Bastian
Gretchen Barnett
Sherry Bardack
Edeneide Barabas
Marilyn Baldwin
Vivian Bailey
Betty Bagdasarian
Robert Autenrieth, Sr.
Cathleen Arnold
Cynthia Arneson
Diane Appelman
Jo Patricia Berger
Lee Berg
Sandy Benson
Gerald Bendele
Sandy Benson
Lee Berg
Jo Patricia Berger
Karen Berkley, Ph.D.
Lynn Berkowitz
Karen Berney
Anne Bernhardt
Patti Bertellotti
Gail Bertiger
Kaye Beth
Joann Bitzer
Rovine Black
Naomi E. Blood
Bruce Boer
Jennifer Boglioli
Ruth Bolson
Susan Bolton
Cindy Bosley
Lynne J. Bowers
Christine Box
Sam Boyce
Mary Ann Boyles
Helen Brandon
Barbara Brandt
Margery Braverman
Carol Bray
Sarah Brink
Joanne Britton
Mary Brodsky
Joanne Brophy
Sylvia Brown
Bonnie Rae Brown
J Brown
Grady Bruce, MD
Kathy Brunning
Sally Bryga
Jacob Buchler
Cathy Bunton
Harriet Burke
Paul Byrne
Marilyn Cadieux
Doris Cain
Sandra Callahan
Janice Callicott
Mary Campbell, Ph.D.
Dorothy Carew
Crystal Carey
Judy Carnaggio
Nancy Carroll
Elaine Cash
Samuel Castrale
Margurita Cauley
Geneva Cecil
Amie Champagne
Gerri Charlebois
Dottie Chase
Elizabeth Chenoweth
Alison Chimerine
Lynn Chiodo
Constance Church-Brady
Mike Cicchella
Mabel Clark
Marianne Clark
Sharon Clarke
Lindsay Cleary
Patricia Coburn-Hintze
Phyllis Cohen
Lori L. Colasante
Judy Coburn
Polly Jo Cook
Dr. Elizabeth Cooney
Teri Lynn Cooper
Charlene Cooper
Armando & Consuelo Corriop
Tate & Keira Coverdale
Eileen Cowin
Mary E. Cowper
Aileen Craig
Patrick Cranston
Diane Crowe
Gail Crowther-Zamore
Donna Curran
Arlene Curry, MD
Judith Cusick
Joe & Angela Daczko
Sandy Davenport
Jane Davis
Mary Davis
Kathryn Dawson
Raymond Dawson
Linda DeBlasio
Barbara Deerkop
Kathy Deimerly
Linda DeLorenzo
Mary Beth DeNiro
Mr. & Mrs. W.P. Denison, Jr.
Jayne DePanfilis
Andrew Deranger, Esq.
Mary Dietz
Ruth Dillon
Charles Dipsinski
Maria Dobriff-Smith
Debra Dodd
Harold Dolehan
Carol Drummer
Melanie Dubs
Anne Duncombe
Cheryl Dunn
Shirley Dunn
Rebecca Dunn
Mildred Ebie
Julie Egeland
Paula Eggert
Marianne Egolf
Ines Ehmer, M.D.
Nada Eichen
Katharine Emerson
Allison Fake
Karim L. Falcone
Amy Farnsworth
Gary Farquharson
F. Joseph Feely, III
Doris Ferlerger-Halbert, Ph.D.
Arlene F. Fields
Dr. Stephen Fike
Laura Firmat
Patricia Fischer
Sandie Fish
Edith Fisher
Judy Fisher
Brenda Flaman
Betty Flanary
Ann Flannery
Patricia Flinn
Madeleine Florin
Charlotte Fogel
Dorothy Fogg
Janice Foley
Sandi Forest
John Forrester
Lynnette Foster
Margaret Foulkrod
Norman B. Fox
Jennifer S. Fox
Linda Fox
Pat Francis
Marilyn Frasure
Susan Freeman
Aimee Freeman Nowak
Anita Freidenreich
Sarah Freifeld
Deborah Frey
Elaine Friedman
Sharon Froemling
David Frow MD
Jane Fuhrman
Janet Gallagher
Ralph Gallienne
Jimmie Garner
Thomas Garver
John Gau
Charles Gaydos
Arshag Gecihiian
Meribeth Geiger
Jayne Gereshkowitz
Loretta Gibbons
Rolland & Lois Gifford
Joe Gill
Edie Gilmore
Gay Giotta
Edith Godar
Eileen P. Goff
Norma Goins
David Goldman
Kara & Steve Goldman
Jennifer Goldsman
Bonnie Goodrich
Joyce Goodwin
Lynn Gores
Andrea Gray
Martha Green
Lillian Green
Megan Greenaway
Lacey Greer
Janet Griffin
James & Peyton Griffin
Joy Guy
Wayne Haegele
Stephanie Haider
Jessie Ham
Lora Hammer
Pam Hancock
Rev. Frederick Campbell Harland
Mark C. Harris
Penelope Harris
Jayne Harrison
Linda Hart
Lisa Haughhey
Patricia A. Hawkins
Patti Hayden
Peggy Hays
James D. Healy
Elesia Heimbecker
Christine M. Heinzle
Becky Held
Billie Hendrickson
Carolyn Kaye Hepburn
Linda Herod
Edna Herrmann, Ph.D.
Cathy J. Hickle
Elizabeth Himan
Sandra Hinchev
Ann Hinds
Julianne Hirsh
Karen Hixon
Jacqueline Hoffman
Kathleen Hohn
Neta Holmes
Pamela Hoover
Judith Hope
Gregory Houston, M.D.
Betty Howlett
Betty Hubel
Sally Humphreys
Jennifer Saltzman Hunt
Georgia Hunt
Patricia Hunter
James Hurt
Leona R. Hutton

www.ichelp.org
Betty Westbrook  
Angela C. Westbrooks  
Kassie Westie, M.D.  
Jerone Whirl descriptive  
Mark and Robin White  
Carolyn White-Krueger  
Maureen Whitlock  
Mary Elizabeth Wier  
William Willetter  
Phyllis Williamson  
Janice Willis  
Patricia Wilson  
Ann Windley  
Michelle Wohlwend  
Joyce Woodruff  
Mary Woodson  
Lila Wrenn  
William Wright  
Sandra Yeager  
Janice Young  
Richard Yowell  
Werner Zarnikow  
Gloria Zavala  
Marilye Zilinskas  
Rosa Zimmer  
Miriam Zolan

**Monthly Donors**

Vivian Bailey  
Larry Barnett  
Catherine Beckley  
Judith Beier  
Bianca Bellesi  
Patti Bertellottii  
Kaye Beth  
Jennifer Boglioli  
J Brown  
Patricia Carter  
Don Cassidy  
Jana Coler  
Sandra Cowen  
Doreen DeBliek  
Kathy Deimerly  
Mary Dietz  
Melanie Dubs  
Diane Dunn, Ph.D.  
Marianne Egolf  
Joe Gill  
Ellen Haas  
Jackie Hansen  
Brenda Hanson  
Laura Hawkins  
Patti Hayden  
Elizabeth Himan  
Julianne Hirsh  
Karen Hisson  
Leona R. Hutton  
Diane Jager  
Carolyn Jacobs  
Ellen Keegan  
Rae Lynne S. Koivu  
Robert Lang  
Bonnie Lee  
Janet Leitch  
Donald Lipscomb  
Sonia Lloyd  
Cynthia Lloyd  
Nicole Fleischer

Donna Mathewson  
Earl McClary  
Teresa McCoy  
Veda “Mickie” Meares  
Nicole Mehall  
Margery Milmore  
Carolyn Mogavero  
Anna Molloy  
Sonja Morgan  
Phyllis Muncez  
Lisa Myers  
Patricia Nicol, M.D.  
Graciela Nieto  
Nola Okerson  
Linda Olsen  
Kennethaylor  
Elaine Perugini  
Anne Redmond  
Janice C. Richmon  
Rachelle Roberts  
Kimberly Rollins  
Patricia Root  
Frances Rosevally  
Ellen Runde  
Susan Santone  
Joyce Schedler  
Mary Ann Schneider  
Minna Schrag  
Marilyn Schreibstein  
Jeanne Scott  
Cheryl Shive  
Terri Smith  
Susan Spence  
John L. Strube  
Ali S. Teitelbaum  
Barbara Thomason, PhD  
Gwen Thorn  
Darlene Tull  
Richard Tall  
Mario Venta  
Lois Vrba  
Shelley Wagoner  
Paula Wheelan  
Leesa White  
DeLana Wicker  
Phyllis Williamson  
Dr. & Mrs. Naoki & Tomoko Yokochi  
Yoshimura  
Rosa Zimmer

**Bequest Donors**

Estate of James & Mary Coyle  
Franklin  
Melanie L. Barton  
Tracey Behn  
Kimberly Billiet  
Florenc Callahan  
Dorothy S. Chase  
Diana Dunn, PhD  
Gregg Dwyer  
Patareka Dwyer  
Lynn Eastburn  
Carol Froese, MD  
Gloria Glasser  
Daniel & Susan Guggenheim  
Cynthia L. Haase  
Donna Huntington  
Kaye L. Kreutzerfeldt  
Barbara McCabe

**Other Donors**

Cheryl Hotard  
Christina Pratt  
Christine Tomolesi  
James Cendejas  
Jeff Cranston  
Jessica Sinacola  
Karen and Kevin Treacy  
Latoya Melancon-Parker  
Patricia Warr

**Volunteers**

Margaret Elizabeth Caughman  
Anderson  
Julie Beyer, RD  
Iliana Brockman  
Patty Cyr  
Gretchen Barnett  
Roxanne Beretta  
Judi Buckalew, RN  
Shawn C. Cummins  
Melanie Dubs  
Loretta Farnsworth  
Maureen Fleming  
Lois Greenfield  
Lori Arnold-Grine  
Bonnie Hana  
Catherine Horine  
Norma Kellar  
Casey Klepchick  
Drew Klepchick  
Tali Krull  
Teresa McCoy  
Kevin Noa  
Daniel Norton  
Nicole Smith  
Lauren Snyder  
Sharon Thompson  
Carin Willis

**Staff**

Penny Allen  
Gary Fackenthal  
Barbara Gordon  
Debi Kerr  
Deborah Lovin  
Nicole Mehall  
Linda Salin  
Marilyn Schreibstein  
Deanne Zwerk