



2008 PROGRESS REPORT  
CONSUMERS ADVANCING PATIENT SAFETY

## DEAR FRIENDS OF CAPS,

Consumers Advancing Patient Safety (CAPS) began in 2003 as a bold voice engaging patients and families in the pursuit of patient safety. Five years ago we started an organization with visions, hopes and dreams that today are the goals that guide us. We continue to make progress toward achieving these goals and to bringing innovative ideas forward.



Over the past five years, CAPS has strengthened its credibility nationally and internationally. We are taken seriously by organizations worldwide, are trusted as a valuable resource by patients and families, and are invited to participate in robust activities to advance the causes of

patient education and patient-centered care both within and outside the United States.

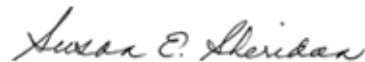
In 2008 we continued to fortify our relationship with the World Alliance for Patient Safety. Through our partnership with the WHO World Alliance and its program Safe Surgery Saves Lives, we held our first focus groups in Buenos Aires with patients from Mexico, Costa Rica, Peru, Ecuador and Argentina. We spoke at conferences and universities in Latin America, and collaborated with professional and patient organizations to raise awareness of patient safety and help develop a network of patient advocates and dedicated healthcare providers and policymakers. We went to Colombia and then to the Nursing Alliance of the Americas in Ecuador to introduce the concept of patient engagement in patient safety.

The CAPS workshop in Chicago introduced powerful topics, including patient reporting, patient involvement in root cause analyses, and defining patient engagement—efforts that are frequently discussed among patient advocacy groups but infrequently developed.

While touting these and other accomplishments outlined in this year's Progress Report, we should also highlight the many challenges that remain, including the underreporting of harm and the fear that keeps us stuck; the lack of a pathway for rapid change that keeps us unsafe; and the lack of infrastructure for the development, nurturing and funding of consumer patient safety organizations.

Have we prevented harm? Have we saved lives? These questions drive CAPS and must continue to be our mantra. Despite our solid foundation and all we have accomplished, we still have so much more to do. We hope you will join us.

Sincerely,

A handwritten signature in cursive script that reads "Susan E. Sheridan".

Susan E. Sheridan, MIM, MBA  
Co-founder and President  
Consumers Advancing Patient Safety



## ABOUT CONSUMERS ADVANCING PATIENT SAFETY

Consumers Advancing Patient Safety (CAPS) is a consumer-led nonprofit organization formed to be a collective voice for individuals, families and healers who wish to prevent harm in healthcare encounters through partnership and collaboration. CAPS is committed to exploring and contributing the wisdom and experience that consumers can offer to patient safety research, education of both consumers and providers, reporting of bad outcomes and near misses, development and implementation of solutions that can prevent harm, and policy making that will help create healthcare systems that are safe, compassionate and just.

We champion the experience and collective voice of consumers who have experienced system failure. And we embrace as partners those dedicated professionals and organizations who share our vision, mission and goals.

## OUR VISION

CAPS envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just.

## OUR MISSION

- To be a champion for patient safety in a new healthcare culture
- To be a voice for individuals, families and healers who wish to prevent harm in healthcare encounters through partnership and collaboration
- To teach the healthcare community what consumers and providers need to know whenever they interact within healthcare systems

## OUR PRINCIPLES, VALUES AND BELIEFS

Our working relationships with each other and with the healthcare community will be guided and governed by the following principles, values and beliefs:

- **COMMITMENT TO THE TRUTH** We believe that being told the truth and telling the truth are vital to restoring health both to patients and to the healthcare system; and that they are essential to sustaining integrity and trustworthiness.
- **OPEN AND HONEST COMMUNICATION** We believe that open and honest communication, based on the principles of transparency and full-disclosure, is the best way to build trust, to minimize breakdowns, and to restore relationships when breakdowns do occur.
- **PARTNERSHIP AND COLLABORATION** We believe in the wisdom, synergy and power of partnership. Engaging in and fostering effective partnerships will be our primary mode of operation and the art of collaboration will be our core competency.
- **EMPATHY AND COMPASSION** We believe in the value of exercising empathy and thereby seeing the world through the eyes of others. We rely on compassion to overcome blame and to guide, motivate and sustain our work.

- **CHALLENGING AND COURAGEOUS CHANGE AGENTS** We believe in serving as strong-willed, persistent advocates for change in the healthcare system and in taking on complex problems or controversial issues that others may choose to ignore, deny or avoid.
- **DIVERSITY AND CREATIVE TENSION** We believe that diversity, in all of its forms, is a valuable asset and a source of strength. We believe that the creative tension, brought about by honest and natural differences, is a catalyst for change and generates optimal solutions.
- **TRANSFORMATION OF ANGER TO ACTION** We believe that anger is an anticipated phase in the healing process and is a signal of hurt, invalidation, or unmet need. We believe in moving beyond anger to resolution and to a commitment for action that will make a positive and significant difference.
- **ACCOUNTABILITY AND FORGIVENESS** We believe that a dynamic balance of accountability and forgiveness contributes to the development of people, systems and cultures that are more responsible, self-correcting and continuously improving.
- **APPRECIATION AND POSITIVE-MINDEDNESS** We believe in discovering and celebrating signs of progress, in acknowledging people for their contributions and in leveraging what is working as the best way to overcome what is not working. The healthcare system will never be perfect, but it can always be better.
- **SYSTEM-ORIENTED AND PATIENT-CENTERED** Our passion for patient safety is founded upon our belief in and our advocacy for a healthcare delivery model that is system-oriented and patient-centered.



## OUR GOALS

GOAL 1: Establish national consumer-led patient safety boards.

GOAL 2: Create local consumer-led patient safety advisory boards in every community.

GOAL 3: Institute non-punitive safety learning/reporting systems.

GOAL 4: Establish an education effort on patient safety for providers and consumers.

GOAL 5: Develop a patient safety awareness campaign that emphasizes patient and healthcare community partnership with trust and open communication.

GOAL 6: Put into place systems that provide just compensation and alternative routes to justice for patients who are harmed in interactions with the healthcare community.

## GOAL 1: ESTABLISH NATIONAL CONSUMER-LED PATIENT SAFETY BOARDS

When it comes to creating and maintaining awareness of threats to patient safety, there is strength in numbers. And because some threats, such as the nursing shortage, are national in scope, they require a nationwide response.

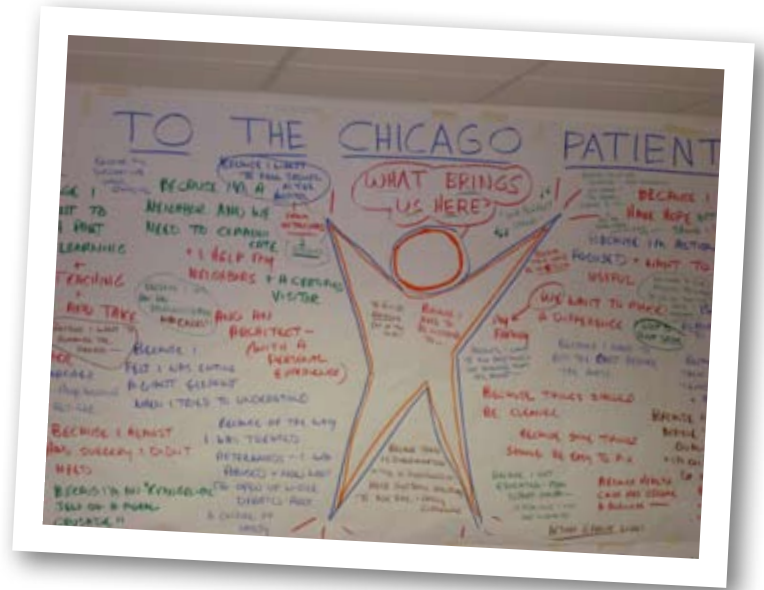
The nursing shortage increases the risk of medical errors and increases the cost of healthcare. It directly impacts our access to care and the quality of the care we receive in hospitals, emergency rooms, doctors' offices, and rehabilitation and long-term care facilities.

In 2008, CAPS was proud to join AARP, the AARP Foundation and the Robert Wood Johnson Foundation as a partner in the national Champion Nursing Coalition, representing the voices of consumers, purchasers and providers of healthcare to help find solutions to the nursing shortage that threatens to escalate into a full-fledged crisis. As part of this coalition, CAPS joins with groups such as the University of Maryland School of Nursing, the Alzheimer's Association, and the American Association of Homes and Services for the Aging.

## GOAL 2: CREATE LOCAL CONSUMER-LED PATIENT SAFETY ADVISORY BOARDS

Hospital leaders and others know there are patients and family members in their communities who would be valuable partners in the pursuit of patient safety. But who are they and how can they be persuaded to join in such a partnership?

"Where there's a will, there's a way," the saying goes. But when it comes to creating local patient safety advisory boards, we often need a guide. There is perhaps no better guide than CAPS member, author and Agency for Healthcare Research and Quality (AHRQ) grantee Kathy Leonhardt, MD, MPH.



**“WE HAVE TO GO TO PATIENTS AND CAPTURE THEIR WISDOM AND KNOWLEDGE, AND FEED IT BACK INTO THE SYSTEM IN A WAY THAT WILL HELP DRIVE CHANGE.”**

**–SUSAN E. SHERIDAN  
CAPS CO-FOUNDER  
AND PRESIDENT**

ACCORDING TO THE 2008 CAPS FEATURE ARTICLE "SHARING KNOWLEDGE TO EMPOWER PATIENTS," TRISHA TORREY – A RADIO TALK SHOW HOST, NEWSPAPER COLUMNIST, BLOGGER, CREATOR OF THE DIAGKNOWSIS WEBSITE AND ABOUT.COM AND WHO WAS MISDIAGNOSED WITH CANCER – BELIEVES THAT MANY PROBLEMS IN PATIENT CARE STEM FROM A LACK OF COMMUNICATION. HEALTHCARE PROFESSIONALS LACK THE TIME TO EXPLAIN MATTERS CLEARLY. PATIENTS HESITATE TO ASK QUESTIONS, OR FAIL TO REPORT SYMPTOMS. LAB RESULTS MAY BE LOST, OR NOT TRANSMITTED PROPERLY. BAD HANDWRITING RESULTS IN MEDICATION ERRORS. EXPECTATIONS OF OUTCOMES MAY DIFFER WILDLY BETWEEN SURGEON AND PATIENT. SOMETIMES, SHE SAYS, THE PROBLEM MAY BE THAT THE WRONG PARTIES ARE TALKING.

- In 2008, Leonhardt, author of the toolkit developed in partnership with CAPS, *How to Develop a Community-Based Patient Advisory Council*, led a free audio conference sponsored by AHRQ to answer questions about how to find and involve patients and family members to serve on patient and family advisory boards.

### GOAL 3: INSTITUTE NON-PUNITIVE PATIENT SAFETY LEARNING/REPORTING SYSTEMS

A medical error occurs...and then what? In Hospital X, someone is blamed and punished and then it's back to business as usual. Because fear is rampant in the organization, the error is swept under the rug, neither examined nor discussed. The problem with this approach, of course, is that nothing changes. If everyone is lucky-- and this is a big "IF" – the error won't happen again. But they could just as easily be "unlucky" a second time, a third time, and more.

The leadership of Hospital Y does not believe in luck. When an error occurs, they and the staff talk about what happened, investigate why it happened, devise ways to prevent it from happening again, and engage healthcare consumers as partners in finding solutions. In 2008, CAPS represented consumers in promoting patient safety through transparency in efforts both national and international in scope.

- In 2008, the Agency for Healthcare Research and Quality (AHRQ) selected CAPS in partnership with RTI International to conduct a 20-month project to develop recommendations for the possible design, development and implementation of a patient safety event reporting system for consumers. As a partner in this project, CAPS will help to identify the types of information to be collected from consumers and recommend the most effective ways to capture it.
- In 2008, CAPS members reviewed and commented on the latest proposed Patient Safety Solutions developed by the WHO Collaborating Centre for Patient Safety Solutions at the request of The Joint Commission International Center for Patient Safety. The Collaborating Centre's top priority is to collaborate with groups worldwide to identify and refine Solutions to support improved patient safety internationally. The Joint Commission also invited CAPS members to comment on the first set of nine Patient Safety Solutions, already in use.

## GOAL 4: ESTABLISH AN EDUCATION EFFORT ON PATIENT SAFETY FOR PROVIDERS AND CONSUMERS

Healthcare providers aim to deliver the safest care they can to patients and families. Healthcare consumers want to know how to ensure their safety whenever and wherever they need healthcare. Yet, because “wishing does not make it so,” we need more than good intentions. We need education.

In 2008, CAPS participated in the following educational efforts for providers and consumers:

- Susan E. Sheridan, Co-founder and President of CAPS, was featured in a new video encouraging providers to embrace patients and their caregivers as partners in their care to co-create a healthcare system that is safe, compassionate and just. The video is part of an introductory education module to the *TeamSTEPPS* initiative, developed by the US Department of Defense (DoD) in collaboration with AHRQ.
- Susan Sheridan’s stories about patients who have experienced medical errors riveted policymakers and others gathered for the launch of the WHO World Alliance for Patient Safety 2nd Global Patient Safety Challenge, Safe Surgery Saves Lives, in Washington, D.C. Sheridan’s personal stories reminded attendees that the consequences of errors are greater than any amount of data can convey—they are personal, painful and profound.
- CAPS collaborated in the Iowa-based train-the-trainer project, “Empowering Public Health/Patient Safety Outreach through Community Partnerships,” or PPECA II. This project, a continuation of the project known as Partnering for Patient Empowerment through Community Awareness (PPECA), is designed to foster partnerships between local medical institutions, public libraries and community members. Its goal is to increase awareness of patient safety and healthcare resources among healthcare educators, consumers and librarians and to improve communication among these groups. Funded by the National Library of Medicine, CAPS partners in PPECA II include the University of Iowa Hardin Library, the University of Iowa College of Public Health and its Institute for Quality Healthcare, the University of Iowa Hospitals and Clinics (UIHC), and Zipperer Project Management.

The CAPS 2008 feature article, “Change One Thing, Change Everything,” tells the story of Victoria Nahum’s 27-year-old stepson, Josh, who died as a result of a bacterial infection at a Colorado hospital following a skydiving accident requiring surgery on his leg. Following Josh’s death, Victoria and Josh’s father, Armando, learned all they could about healthcare-related infections and began to educate others by creating the website [www.Safecarecampaign.Org](http://www.Safecarecampaign.Org). With the help of the CDC, the Association for Professionals in Infection Control (APIC) and the sponsorship of Kimberly-Clark, the Nahums also produced a safety video to be shown to patients and families at the time of hospital admission.

Her advice to others who want to get involved in patient safety education efforts? “Stick with what you know. Build on talents you already possess for the benefit of the patient safety community... Change one thing, change everything.”



- CAPS facilitated a workshop in Chicago to advance partnerships to improve patient safety. The workshop focused on reporting medical errors and “near misses,” root cause analyses and medical system failures, shared decision-making, making patient experiences part of the research agenda and involving patients and family members as partners in their care. CAPS partners in this effort were Northwestern Memorial Hospital in Chicago, the WHO Patients for Patient Safety Program, the Pan American Health Organization and Partnership for Patient Safety.
- CAPS continued to contribute to the magazine *Patient Safety & Quality Healthcare* which, with a circulation of 15,000, focuses on technology, training, case studies in safety improvement, consumer concerns and products that promote safe and effective care in a variety of clinical settings.
- CAPS was once again an endorsing organization of National Family Caregivers Month, celebrated every November, in a nationally recognized time set aside to thank, support, educate and empower more than 50 million family caregivers across the country who provide more than \$350 billion in “free” caregiving services.

The 2008 CAPS feature article about Trisha Torrey, “Sharing Knowledge to Empower Patients,” explains how her cancer misdiagnosis led her to champion patients’ rights to information, ask questions of their healthcare providers, discuss diagnosis and treatment options, seek second opinions, and change providers, if necessary. Trisha reaches out to patients to let them know they have a right to information and devotes her life to helping them find it.



## GOAL 5: DEVELOP A PATIENT SAFETY AWARENESS CAMPAIGN THAT EMPHASIZES PATIENT AND HEALTHCARE COMMUNITY PARTNERSHIP WITH TRUST AND OPEN COMMUNICATION

If it “takes a village” to raise a child, it takes a community—with healthcare providers and leaders talking and working in partnership with patients and families—to realize the goal of patient safety. It also takes an honest broker to put these groups together and get them talking.

- In 2008, CAPS served as this honest broker, bringing healthcare consumers, providers, policymakers, and payers together through the “Add Patients, Change Everything!” campaign, which will continue into 2009. Through this campaign, sponsored by sanofi-aventis US LLC, CAPS selected Johns Hopkins Hospital in Baltimore, the Colorado Patient Safety Coalition in Denver, and the Arizona Hospital and Healthcare Association in Phoenix to host community-based consumer engagement workshops. The goal of these workshops is to promote dialogue between patients and providers in these communities on subjects including effectively responding when errors occur, engaging patients and families in quality improvement and establishing a community culture of patient safety.

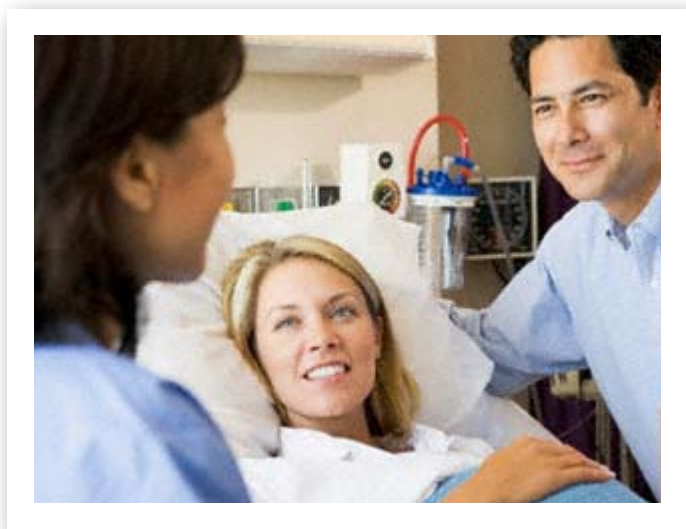
## GOAL 6: PUT INTO PLACE SYSTEMS THAT PROVIDE JUST COMPENSATION AND ALTERNATIVE ROUTES TO JUSTICE FOR PATIENTS WHO ARE HARMED IN INTERACTIONS WITH THE HEALTHCARE COMMUNITY

Patient safety is the goal of every healthcare provider and medical institution. Yet, things can and do go wrong, patients are harmed, and patients and families suffer unimaginable consequences as a result. The question then becomes, how should healthcare institutions respond in such situations?

When a patient is harmed by a medical error, some hospitals and healthcare providers may choose to “deny and defend,” costing them not only hundreds of thousands of dollars in legal fees in addition to damages but, more

importantly, the good will and loyalty of patients and families. Alternatively, hospitals may choose to establish policies allowing healthcare leaders and providers to talk openly with patients and families about what went wrong and why, and to compensate patients fairly, avoiding unnecessary court costs and gaining customer loyalty in the process.

- In 2008, CAPS supported The Joint Commission's Annual Conference on Quality and Safety for organizational leaders interested in pursuing the latter course. In its 22nd year, the conference focused on decisions and actions for healthcare executives seeking to improve quality and reduce errors, contain costs, increase productivity and more.
- Because stories offer perhaps the most unforgettable and powerful lessons about the ability of one person to make a difference, CAPS published a feature article about Leslie Worthington of Manitoba, Canada. In the wake of her father's death as a result of what she describes as negligence, Leslie fought for information, respect, and honest dialogue about what went wrong, why, and what the hospital would do to prevent such outcomes in the future. Only partially successful in her quest for truth and justice, the article describes Leslie's advocacy efforts, resulting in the passage of The Apology Act by the Manitoba legislature in November 2007.



DUE TO LESLIE  
WORTHINGTON'S  
PERSISTENT EFFORTS,  
MANITOBA'S APOLOGY  
ACT WILL, SHE HOPES,  
MAKE IT EASIER FOR  
HEALTHCARE WORKERS  
TO SAY "I'M SORRY" –  
WORDS PATIENTS AND  
FAMILIES DESPERATELY  
NEED TO HEAR WHEN  
SOMETHING GOES  
WRONG IN THEIR CARE  
– WITHOUT FEARING  
LEGAL RAMIFICATIONS  
OR PUTTING THEIR  
CAREERS AT RISK.

## 2008 CAPS APPOINTMENTS TO THE BOARD OF DIRECTORS

In 2008, CAPS appointed three new members to the Board of Directors: Dennis S. O'Leary, MD, Janet Jacob, MBA, RN, and Nancy Reller, to help advance the organization's vision, mission and goals.



**DENNIS S. O'LEARY, MD**

Dr. O'Leary, President Emeritus of The Joint Commission, will help provide support to CAPS in promoting patient-centered healthcare. During Dr. O'Leary's 21 years as president, The Joint Commission successfully

transformed its accreditation process to focus on actual organization performance in the provision of patient care. This transformation set the stage for the progressive introduction of care-related outcomes and process measures, as well as National Patient Safety Goals, into the accreditation process.

Dr. O'Leary is highly active in a variety of professional activities, and was recently identified by Modern Healthcare as "one of the 25 most influential leaders in healthcare" during the past quarter century. Dr. O'Leary was also awarded the 2005 Distinguished Service Award, the highest honor from the American Medical Association, for his advancement of healthcare quality and patient safety.



**JANET JACOB, MBA, RN**

Janet Jacob is corporate patient safety officer and director of Corporate Clinical Resources for Adventist Health System. She is responsible for providing leadership for multiple Adventist Health

System Clinical Initiatives. Jacob previously served in numerous hospital clinical operational roles as the Joint Commission Coordinator, Policy and Procedure Coordinator, Director of Patient Care Systems, Director of Clinical Staffing Resources and Director of Venous Access at Florida Hospital.



**NANCY RELLER**

Nancy Reller is president of Sojourn Communications, a public relations firm specializing in healthcare. A believer in well developed strategic planning and thorough, precise implementation, Reller likes to tackle the tough issues that face Americans. Her experience

has taken her into the worlds of nursing homes, hospital systems, end-of-life care, chronic illness, aging, women's issues, mental health, organizational renewal, and family planning and reproductive health.

In addition to O'Leary, Jacob and Reller, members of the CAPS board include directors Geraldine H. Amori, PhD, ARM, DFASHRM, CPHRM; Martin J. Hatlie, JD; Jonathan C. Peck; Susan E. Sheridan, MIM, MBA; Ryan Sidorchuk, BA, CRS; and Debora Simmons, RN, MSN, CCRN, CCNS.

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Mitchell L. Dvorak



## CONTRIBUTORS AND PARTNERS

Consumers Advancing Patient Safety greatly acknowledges the following for their contributions to further the mission of CAPS that envisions a partnership between consumer and providers to create global healthcare systems that are safe, compassionate and just.

Thanks for making our work possible.

Agency for Healthcare Research and Quality  
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Corporate Patient Safety Officer, Director  
Corporate Clinical Resources  
Adventist Health System - Office of Clinical Effectiveness  
DeBary, FL

International Alliance of Patients' Organizations  
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Joint Commission International Center for Patient Safety  
Oakbrook Terrace, IL

The Joint Commission  
Oakbrook Terrace, IL

E.W. Kaiser  
Dearborn, MI

Linda K. Kenney  
Founder, President and Executive Director  
Medically Induced Trauma Support Services (MITSS)  
Chestnut Hill, MA

Kathryn Leonhardt, MD, MPH  
Delafield, WI

Alan Levine  
Washington, DC

Yves Longtin  
Quebec City, QC  
Canada

Sharon Martin  
Houston, TX

Rebecca and Alexander Martins  
Warren, ME

David Mayer  
Buffalo Grove, IL

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Medically Induced Trauma Support Services (MITSS)  
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President and Senior Futurist  
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Ryan Sidorchuk, BA, CRS  
Vice President  
Consumers Advancing Patient Safety  
Leader, Patient Voice Facilitation  
Winnipeg Regional Health Authority  
*Winnipeg, MB*  
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Debora Simmons, RN, MSN, CCRN, CCNS  
Director  
Consumers Advancing Patient Safety  
*Pearland, TX*

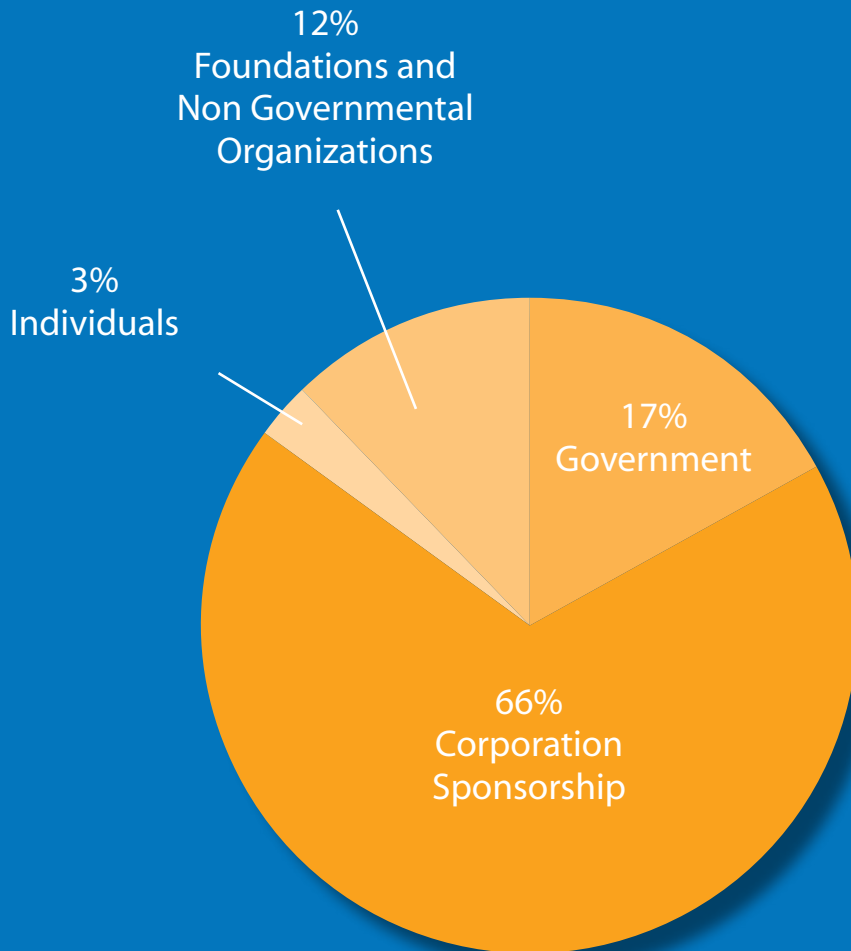
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*Tinley Park, IL*

Otho S. A. Sprague Institute  
*Chicago, IL*

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Lorri Zipperer, MA  
Zipperer Project Management  
*Evanston, IL*

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## ACKNOWLEDGEMENT

The CAPS 2008 Annual Progress Report was written by Eve Shapiro, a Bethesda, Maryland-based medical writer dedicated to improving communication between physicians and patients to enhance patient safety and reduce medical errors. Emails to: [eve@shapiromedicalwriting.com](mailto:eve@shapiromedicalwriting.com)

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Donations of any size help us to further the mission and vision of Consumers Advancing Patient Safety (CAPS) to create global healthcare systems that are safe, compassionate and just. Consumers Advancing Patient Safety, incorporated in Illinois in 2002, has received recognition from the U.S. Internal Revenue Service as a tax exempt public charity under Section 501(c)(3) of the Tax Code. Donations to CAPS are fully deductible based on Section 170 of the Internal Revenue Code less any goods or services provided in exchange for the contribution.

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