

*We cannot assume that health  
have a critical opportunity to make healthcare  
unique and valuable*

2009 PROGRESS REPORT  
Consumers Advancing Patient Safety



*APPS offers a variety of users  
bring specialized knowledge, skills and roles*

**CAPS**

Consumers Advancing Patient Safety®



# Dear friends

DEAR FRIENDS OF CAPS,

Leaders in the worldwide patient safety movement are helping spread the word about the importance of patient engagement when it comes to patient safety. Here at CAPS, we couldn't agree more. We know that patients and family members working in partnership with the healthcare community continue to drive the real change needed to ensure safety, both in the U.S. and across the globe.

Whether they are patients, caregivers or clinicians, all of these leaders have stories to tell.

Take the story of Atlanta's Victoria Nahum, whose son survived a skydiving accident but lost his life to a hospital infection during recovery. Victoria is now an active patient safety advocate, speaking out about the importance of hand hygiene as the key to preventing hospital-acquired infections.

Then there's the story of Evangelina Vasquez of Mexico, whose son suffered brain damage from a hospital acquired infection and untreated newborn jaundice. She has since become a strong voice for patient safety throughout Latin America, addressing the issues of testing newborns for jaundice and infection control in urban hospitals as well as remote mountain villages.

Jorge Martinez, M.D., an Argentinean pediatrician and fervent advocate for patient-centered care, educates parents so they can make informed decisions about their children's health. In addition, he runs a World Health Organization (WHO) pilot program introducing their patient safety curriculum. Dr. Martinez's involvement in the movement began when he attended his first workshop back in 2007 convened by CAPS, WHO and The Joint Commission.

People's stories explain their reasons for getting involved, and they keep us at CAPS motivated to continue our efforts. In this Progress Report, you'll read about the significant strides we took in 2009 to broaden awareness and initiate new systems so that stories of medical error can stop.

I strongly believe in what we've done, but there's still so much more to accomplish. The collective drive, ingenuity and resources of the members of the patient safety movement help disrupt healthcare's status quo, moving it in a positive direction through collaboration and advocacy.

When you think of your role in ushering patient safety toward its goals, what story can you tell? Whether it's through financial support, leadership, volunteerism or all of the above, your contributions can enable happy endings.

Sincerely,

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

“ Sharing our stories becomes a form of therapy for a broken healthcare system. Stories told with compassion heal the tellers and the listeners. ”

Annette Simmons, M.Ed.  
President  
Group Process Consulting  
and author of *The Story Factor*



*We cannot assume that  
healthcare is safe.*



## 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.

“ It’s been very exciting to see CAPS emerge and flourish, because the consumer’s voice is critical. Having consumers participate to improve safety and quality is a game changer. ”

Carolyn Clancy, M.D.  
AHRQ Director



*CAPS offers a variety of useful ways and resources to improve patient safety.*

## 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.



*Consumers have a critical opportunity to make healthcare safer.*

- **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 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 FOR THE NEAR FUTURE

- Establish a national education/awareness and communications effort
- Play a leadership role in patient safety advocacy
- Help build coalitions for patient safety
- Gain funding to build infrastructure





Fifteen years ago, the Dana-Farber Cancer Institute killed a patient because the institution simply wasn't hearing her complaints. After that, we began a journey inviting patients and families to join every single body within our decision-making structure. Now, Dana-Farber is recognized as having best practices when it comes to patient safety and consumers want what they see happening here. It's a difficult process, but there's no confusion: there's nothing more important.

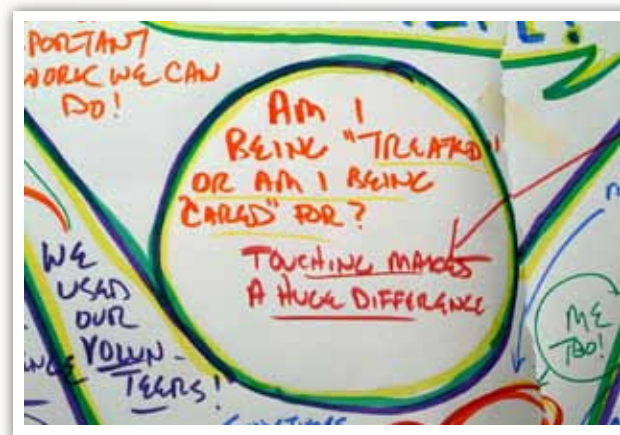


Jim Conway  
 Former COO, Dana-Farber Cancer Institute  
 Senior Fellow at Institute for Healthcare Improvement  
 Co-Chair with Sue Sheridan of IHI Open School  
 Course on Patient and Family Engagement

## THE EXPANSIVE REACH OF CAPS

Members of the CAPS leadership team and volunteer corps are affiliated with numerous councils, committees and task forces, which help to connect our efforts with the important work of other organizations committed to patient safety. Here are some of the groups with which CAPS representatives are involved:

- National Transitions of Care Coalition (Advisory Task Force)
- Nursing Alliance for Quality Care (Board of Directors)
- World Health Organization (Patient Safety Programme, Patients for Patient Safety Steering Group)
- National Patient Safety Foundation (Board of Governors)
- Patient Safety and Quality Healthcare Magazine (Editorial Board)
- Joint Commission Patient and Family Advisory Council (Member)
- Institute for Healthcare Improvement (Co-chairs of Open School course on Patient and Family Engagement)
- National Quality Forum (Member)
- International Alliance of Patients' Organizations (Member)
- National Council on Patient Information and Education (Member)



The Open School course was originally designed as a disruptive innovation to provide healthcare professionals with training they weren't otherwise receiving on issues of quality and safety. But once we got it off the ground, we were astounded at the amount of interest. It's turned into a non-disruptive innovation because students, deans and faculty members are embracing it and we're seeing amazing growth. It speaks to the importance of what CAPS, IHI and other organizations are doing: we're all collaborating to help healthcare students and professionals talk about patient and family care.



Jim Conway  
 Senior Fellow at Institute for Healthcare Improvement  
 Co-Chair with Sue Sheridan of IHI Open School Course  
 on Patient and Family Engagement

## A BROADENED ORGANIZATIONAL STRUCTURE

In the past year, CAPS strengthened its own foundation by adding to the board of directors and expanding the reach of its committees. In addition, CAPS gained even greater recognition when two members of its leadership team were named among the nation's most influential individuals in healthcare.



*CAPS is a unique and valuable partner in the patient safety movement because CAPS brings the collective consumer voice to the table.*

## NEW CAPS BOARD MEMBERS ROUND OUT THE LEADERSHIP TEAM



**Helen Haskell.** The preventable death of her teenage son in 2000 brought Helen to her patient safety advocacy role. Founder of South Carolina-based Mothers Against Medical Error, Helen has been deeply involved in the patient safety movement and is passionate about improving support for patients who have experienced medical injury.



**James Padilla, JD.** After he lost his six-year-old to medical error, Jim dedicated himself to patient safety, emphasizing the importance of the nurse's role in ensuring proper care and the need for families to stay engaged in the process when something goes wrong. Jim is a World Health Organization Patients for Patient Safety Champion and has been a member of CAPS since 2007.



**Alan Levine.** Al brings professional and personal experience to his role on the CAPS board. Prior to his retirement in 2008, Al worked for the Department of Health & Human Services, where he coordinated more than 100 national studies of HHS programs. His mother's death from medical error in 1998 propelled him toward advocacy, and he brings his passion for patient safety to his role with CAPS.



**Rebecca Martins.** Becky was already a strong believer in patient advocacy when she lost her father in 2000 from a preventable death related to his kidney disease. Her commitment to the cause broadened to include patient safety and she has since become involved in such organizations as the National Patient Safety Foundation's Patient and Family Councils, the World Health Organization's Patients for Patient Safety Programme, the Maine Quality Forum Advisory Council and numerous consumer healthcare organizations.

“Expanding the CAPS board helps facilitate the organization's mission. When you have members of the board who are grassroots advocates and medical error victims (as Jim, Becky, Al and I are), then you have more focus on the mission. We concentrate on the purpose rather than the process.”

I see part of my mission as keeping people in touch and networked. It's gratifying because I can see the patient safety movement growing closer and more unified in the past couple of years. CAPS' work is part of that development, and it's very positive.”

Helen Haskell  
CAPS Board Member



*CAPS empowers consumer-led partnerships to bring specialized knowledge, skills and voices together in a collaborative voice.*

## COMMITTEES HELP FOCUS THE CAPS MISSION

New committees help define the efforts of our board members and our deep pool of volunteers. In 2009, we established the following official committees, each of which operates on a specific set of goals:

- Communications and membership
- Governance
- Programs
- Finance and development
- Advocacy and policy



*I joined CAPS not just because of what my family went through, but to help patients and family members be considered serious members of the care team; to help convey the value that our perspective brings. CAPS is actively working to improve the direction of healthcare by getting consumers involved and letting the patient voice be heard. And even though we're fighting against the tide, we're making great progress in gaining recognition and credibility. The CAPS mission is about more than saving lives. It's about creating better, safer, more effective healthcare.*

Jim Padilla, JD  
CAPS Board Member



## CAPS LEADERS NAMED TO PRESTIGIOUS LIST

CAPS Co-founder and President Susan Sheridan and CAPS Board Member Helen Haskell were both included in Modern Healthcare magazine's prestigious 2009 list, "100 Most Powerful People in Healthcare."

Chosen from more than 25,000 nominees, Sheridan and Haskell were named alongside President Obama, Kathleen Sebelius, U.S. Secretary of Health and Human Services, and Nancy-Ann DeParle, Director of the White House Office of Health Reform. They were ranked 38 and 51, respectively.

"I am very honored to be included on this list," said Sheridan. "I hope this recognition will inspire others to join CAPS, as we help patients to play a proactive role in their personal healthcare safety, and to play an advocacy role in the patient safety movement."

Haskell added, "Patients have a critical opportunity to make healthcare safer, and CAPS is a unique and valuable partner in the patient safety movement because this organization brings the collective consumer voice to the table."



## A ROBUST LIST OF ACCOMPLISHMENTS

We've been very busy continuing our legacy projects while rolling out new initiatives in the past year. Here are the highlights of what we've been working on:

**Consumer Engagement Workshops.** CAPS hosted "Add Patients, Change Everything" workshops in Denver, Baltimore and Phoenix in 2009. We invited patients, family members, practitioners and patient safety community-based programs to participate in discussions and information exchange on the subject of community-based partnerships that advance patient safety in America and across the globe.

**Transitions in Care Toolkit.** CAPS released a new tool called *Taking Charge of your Healthcare: Your Path to Being an Empowered Patient*. This comprehensive kit is designed to assist patients and family members with the crucial time when they are transitioning away from in-patient care. Whether they are bound for home or another clinical facility, patients will find useful information and resources within the toolkit.

**UK Patient and Public Reporting Review Project.** CAPS is offering our expertise to review the U.K. National Patient Safety Agency's patient and public reporting system and providing recommendations to increase reporting from patients and the public and reduce barriers to reporting.

**Consumer Reporting Project.** CAPS is collaborating with RTI International on developing recommendations for a framework for patient safety event reporting systems for consumers. Sponsored by the Agency for Healthcare Research and Quality (AHRQ), the initiative aims to design specifications for patient reporting systems of medical errors and other adverse safety occurrences.

**Diagnostic Errors in Medicine Project.** CAPS is honored to provide the consumer perspective and participate on the Technical Expert Panel of AHRQ's grant, Developing Patient Safety Interventions to Reduce Diagnostic Errors in the Ambulatory Care Setting.

“ For so long, I've felt alone and discouraged, thinking nobody in healthcare really cared about what happened to my family or what I had to say about it. For the first time in years, I feel real hope. It was so energizing being with a group who I believe really are going to do something. ”

Attendee of the 2009 Baltimore Patient Engagement Workshop

“ The CAPS workshops are an invitation to bring patients and providers together to have a conversation they don't typically have an opportunity to have; a conversation that some organizations are a bit hesitant to engage in because it sometimes means acknowledging that we don't provide perfect healthcare. The workshops bring providers and patients together to think about how we might do things better. These are unprecedented discussions. ”

Lori Paine, RN, MS  
Director, Patient Safety, Johns Hopkins  
Hospital  
CAPS Consumer Engagement  
Baltimore Workshop Coordinator



## TOOLS AND RESOURCES

CAPS is proud of its growing library of materials that document and inform the global patient safety movement and help demonstrate our broadening reach. Our website contains the following new tools:

**New and Improved Resource Collection.** Our current online resources collection provides tools and information that are equally useful to consumer and professional audiences. We have significantly increased the number of items available through the collection, and improved the way information is catalogued. New content is added regularly, and all new articles, books, tools and other resources are annotated for easy identification. The content is separated into four main categories:

1. Patient Safety
2. Communication Education
3. Administration
4. General Medical Information

**Chicago Workshop Video.** Visitors to the CAPS website may view the video of our kick-off patient engagement workshop held in Chicago in 2008. This extremely powerful event brought together 90 individuals representing both the patient and provider sides of healthcare. The video summarizes the important accomplishments of the workshop and captures the stories that compelled the participants to take part.

**AHRQ Podcast.** CAPS has posted a podcast (as well as a transcript) featuring an interview with Dr. Carolyn Clancy, director of the Agency for Healthcare Research and Quality. In the three-minute interview, Dr. Clancy touches on how healthcare organizations in the U.S. are working to reduce healthcare risks and improve healthcare quality. She also discusses the AHRQ-funded project with Aurora Health Care in partnership with CAPS and Midwest Airlines to build a community-based patient safety advisory council in Walworth County, Wisconsin.



“ I worked with a young woman named Kathy who died unnecessarily of pulmonary embolism while waiting for lab tests in the ER. I felt compelled to contact the quality assurance team at the hospital and request a review of the case. Because of my familiarity with patient engagement, I knew how to go through those channels; I knew I had the right to ask. We can't do anything to bring Kathy back, but if we can improve things for other patients who present with the same symptoms then these efforts are well worth it. ”

Linda Walton, M.L.S.  
Manager of CAPS Resource Collection  
Associate University Librarian & Director,  
Hardin Library  
for Health Sciences  
University of Iowa

## A BRIGHT FUTURE FOR PATIENT SAFETY

We are constantly looking for new ways to spread the patient safety word via an expanded set of resources and innovative methods of engaging all audiences in the discussion. In the coming months, we will be launching many new programs. Among them:

**CAPS Consumer Engagement Workshop:** Transforming Patient Safety through Effective Partnerships. CAPS has leveraged the success of the four consumer engagement workshops held in 2008 and 2009 and will now make the workshops available to hospitals and other groups throughout the country on a consulting basis. A full brochure describing the features and benefits of the workshops is available on the CAPS website.

**New Consumer Guide.** CAPS is collaborating on an initiative funded by the AHRQ and led by the American Institutes for Research to develop a Guide to Patient and Family Engagement. The purpose of the Guide is to promote patient and family engagement in hospital settings and aims to expand on existing efforts to facilitate patient and family engagement through the creation of evidence-based guidance and tools that will create a foundation for culture change. CAPS is working alongside Carilion Health Clinic, the Institute for Family-Centered Care, the Joint Commission, the Health Research and Education Trust, Planetree, the Maryland Patient Safety Center and Aurora Health Care.

**WHO Videos.** CAPS will continue to collaborate on World Health Organization (WHO) videos that highlight consumer involvement in healthcare initiatives around the world. Each captures patients, healthcare practitioners and policy makers working in partnership to create global awareness of patient safety. We are currently in production on several new region-specific videos that document the once-absent patient voice in the worldwide discussion of strategic healthcare planning. The videos will appear on the CAPS website.

**Consumer Reporting Project.** CAPS, along with RTI International, will issue the final report on this two-year collaborative AHRQ-sponsored research project in the coming months. The report will include findings and recommendations related to the development of a comprehensive adverse event reporting system for the American healthcare community.



“ Going to the CAPS workshop in Denver was a hard two days because it taught me more about what happened to my daughter. But I also learned that there are a lot of other people who have experienced the same thing. It was my official foray into the community of people asking why these mistakes are being duplicated and demanding that the system be fixed. I’m now getting a Master’s in Patient Safety because I can’t stand the way things are. The CAPS workshop connected me with people who have a vision to make things better. ”

*Carole Hemmelgarn  
Denver Consumer Engagement Workshop Participant*



## 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  
U.S. Department of Health and Human Services  
Rockville, MD

American Association of Critical-Care Nurses  
Aliso Viejo, CA

American Institutes for Research  
Washington, DC

Arizona Hospital and Healthcare Association  
Phoenix, AZ

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Milwaukee, WI

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Tessa Burton  
Chicago, IL

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Canada

The Chest Foundation  
Northbrook, IL

Coalition for Quality and Patient Safety of Chicagoland  
Chicago, IL

Colorado Patient Safety Coalition  
Denver, CO

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Harvey, IL

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National Family Caregivers Association  
Kensington, MD

National Transitions of Care Coalition  
Little Rock, AR

Northwestern Memorial Hospital  
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Research Triangle Park, NC

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Patients for Patient Safety Programme  
Geneva, Switzerland

Sherry Worsham  
Grenada, MS

Lorri Zipperer, MA  
Zipperer Project Management  
Albuquerque, NM



## A LITTLE GOES A LONG WAY

Every dollar donated to CAPS goes toward furthering our important mission of eradicating medical error. Here are a few examples of what your contribution can accomplish:

- \$50 will help ensure free access to patient safety information for one patient or family caregiver
- \$75 will subsidize a patient safety training session for healthcare providers
- \$100 will help a community-based advisory board replicate medication safety tools
- \$500 will help underwrite the cost of attendance for a healthcare consumer to share their personal experience with healthcare providers at a patient safety conference

## DONATION FORM

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.

**FOR CREDIT CARD DONATIONS PLEASE GO TO [WWW.PATIENTSAFETY.ORG](http://WWW.PATIENTSAFETY.ORG)**

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Consumers Advancing Patient Safety | 405 N. Wabash Ave | Suite P2W  
Chicago, IL 60611

For more information or credit card donations please go to **[www.patientsafety.org](http://www.patientsafety.org)**

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