

May 30, 2007

THE INFORMED PATIENT

By LAURA LANDRO



Patients, Families Take Up The Cause of Hospital Safety

Grass-Roots Movement Offers Support, Information to People Affected by Medical Errors

When her 18-month-old daughter Josie died after a series of medical mistakes at Johns Hopkins Children's Center in Baltimore six years ago, Sorrel King was consumed by grief and anger, wanting to destroy the hospital and even end her own life. But with three other children to live for, she and her husband Tony decided they had to help fix a broken system.

"We had to do something good that would prevent this from ever happening to a child again," Ms. King says. When the hospital offered a financial settlement, Ms. King, a former fashion designer who had become a stay-at-home mom, asked Johns Hopkins to take some of the money back to start a children's safety program. She also created the Josie King Foundation to fund safety initiatives at other hospitals.

Now, to take the message to a broader audience of both consumers and medical professionals, she is launching a new Web site, josieking.org¹, with her own blog on patient safety; an online community where families can post their medical-error experiences and provide emotional support; advice from medical and legal experts on how to avoid error and deal with it when occurs; and resources for hospitals seeking to improve safety.



The King family

Sorrel King in 2000 with her daughter Josie, who died a year later at age 18 months.

experienced harm.

One group, Consumers Advancing Patient Safety, which launched its own online community two months ago, was tapped by the World Health Organization to help build a global network of consumer patient-safety champions, conducting patient-safety workshops around the world.

According to the Geneva-based organization, part of the United Nations, an average of one in 10 patients

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world-wide admitted to a hospital suffers some form of preventable harm that can result in severe disability or death. The additional hospitalization, litigation claims, hospital-acquired infections, lost income, disability and medical expenses cost some countries between \$6 billion and \$29 billion a year, the group says.

Sue Sheridan, a CAPS board member now working with the WHO Patients for Patient Safety project, experienced two tragic adverse medical events: Her son Cal's neonatal jaundice went untreated, leading to a kind of severe brain damage called kernicterus, and her husband Pat died after a cancer diagnosis wasn't communicated, resulting in a six-month delay in treating his condition.

Ms. Sheridan says one of the last things her husband told her before his death was, "Never give up on patient safety." The message, she says, "was seared in my soul." (Ms. Sheridan's evolution as a patient advocate was chronicled in a [Feb. 6 page-one article](#)² in The Wall Street Journal.)

Others doing work in this vein include Jennifer Dingman, who co-founded Persons United Limiting Substandards and Errors in Health Care (<http://www.pulseamerica.org>)³ after losing her mother to a series of preventable medical errors; a related group, Pulse of New York, was started by Ilene Corina after her 3-year-old son bled to death following a tonsillectomy. Cathy Lake started the surgicalfire.org Web site to alert consumers to the risk of fires from electrical equipment used during surgery after her mother was severely burned and subsequently died after a series of complications and treatment errors.

And caregivers are joining, too. After a routine surgery led to complications that nearly killed her, Linda Kenney joined with the anesthesiologist who had been involved, Rick Van Pelt, to form Medically Induced Trauma Support Services (MITSS.org)⁴, which provides support and other resources for both families and medical professionals.

"These people are the real heroes of patient safety, putting themselves at risk by going back into the same burning building and reliving their experiences to help someone else," says Charles Denham, a physician and hospital-safety expert who is chairman of a number of patient-safety programs. Dr. Denham's nonprofit Texas Medical Institute of Technology funded a video in which Ms. King describes the medical errors that led to Josie's death; it is now used as a training tool by hospitals.

Ms. King, who had another child after Josie's death -- she now has two daughters and two sons -- says one of her chief aims is to convey the importance of the family as the patient's advocate in a hospital. And she says it is critical for caregivers to listen to families' concerns. Rushed to the hospital with severe burns suffered when she accidentally stepped into a scalding tub at home, Josie was responding well to treatment in the intensive-care unit. But after she was moved to an intermediate-care unit, she began to exhibit unusual symptoms, such as furiously sucking on a washcloth and crying for every drink she saw.

Turning Anger into Activism	
Patient safety groups launched by victims of medical error	
Organization	Description
Josie King Foundation josieking.org	Consumer patient-safety information; hospital safety programs; online forum to share medical error experiences.
Consumers Advancing Patient Safety patientsafety.org	Patient-safety information; online forums on medical error experiences.
Persons United Limiting Substandards and Errors in Health Care pulseamerica.org	National network of patient-rights advocates and victims of medical errors; links for patient rights, chat rooms.
Surgicalfire.org	Information on surgical-fire risks and prevention.
Medically Induced Trauma Support Services MITSS.org	Education and support for patients, families and medical professionals involved in errors.

Despite her mother's warnings and expressions of concern, hospital staff overlooked or misinterpreted mounting signs of severe dehydration, and gave her a narcotic despite verbal orders that she receive no further medication. She died two days before she was scheduled to go home.

"The day Josie died, it hit me so hard it was like being struck by lightning," Ms. King recalls. "For months and years I kept searching for a reason, and gradually I began to see that there was one." As she began traveling the country to speak at health-care conferences, "I realized I could make a little bit of difference," she says. "They all know there is a problem, and they want desperately to solve it."

Rick Kidwell, the Johns Hopkins attorney who handled the case, was the first person Ms. King called about using some settlement funds to start a patient-safety program. He is now one of several experts who offer commentary and advice about patient safety on the new Web site, including Peter Pronovost, medical director of the Johns Hopkins Hospital's Center for Innovation in Patient Care.

Mr. Kidwell is also now director of risk management at the University of Pittsburgh Medical Center, where the Josie King Foundation has been sponsoring a pilot program called Condition Help. It's a hot line families can call to summon a "rapid response" team of specialists inside the hospital if they feel that a patient is in danger and isn't receiving the necessary attention.

Beth Kuzminsky, a nurse and associate at UPMC's Center of Quality Improvement and Innovation, says at first the program was unsettling to doctors and nurses, who worried that it would scare patients, and would reflect badly on them if a family used the call line. But staffers were convinced that the system wouldn't be abused by patients.

Since July 2005, a Condition H has been called 62 times, she notes. And the data suggest that 69% of the incidents would have led to potentially harmful patient situations if Condition H hadn't been called. The program will be expanded in January to all of UPMC's 14 acute-care hospitals.

Ms. King advises families to record important medical information while in the hospital, including when and by whom medical procedures were performed and the names of the doctors and nurses on duty each day. Her foundation has created a "Care Journal" with space for jotting down the information. Ms. King says she is in talks with UPMC, Johns Hopkins and Duke University Medical Center about providing the journals to patients and families.

Ms. King says it is equally important to help medical staff who have been involved in errors or adverse events, because there is often no formal help with the emotional fallout of being involved in patient harm.

And nurses and doctors may be told to keep quiet and avoid contact with the patient or family in case of a lawsuit. One of her foundation's programs, "Care for the Caregivers," includes a course to teach intensive-care nurses how to write about stressful situations at work, to help sort out their emotions.

"It isn't just the family and patient who suffer when there is a medical error," says Ms. King. "It's also devastating to the caregiver, and there is not much of a support system."