Champion of Change

Sorrel King, Parent and Family-Centered Care Advocate

When a freak bathtub incident left toddler Josie King with second-degree burns over 60 percent of her body, her mother Sorrel King was thankful that they had taken Josie to one of the finest medical facilities in the world – Johns Hopkins in Baltimore, Maryland.

“I remember walking down the hospital corridors and passing poster after poster proclaiming Johns Hopkins as the best hospital in the world and my husband Tony and I were thankful that’s where Josie was. We were at Johns Hopkins. What could go wrong?”

But something did. After two weeks in the hospital being nursed back to health, and just a couple of days before her discharge, Josie King’s heart suddenly stopped. Sorrel King had noticed warning signs – her daughter’s insatiable thirst, vacant eyes and rapid weight loss. But when she voiced her concerns she was ignored, told that Josie was fine. Two days later, Josie was removed from life support. She was 18 months old.

Josie’s death was caused by dehydration. But the real culprit was lack of communication between and among key medical staff, and a failure to respond to Sorrel when she voiced concern about Josie’s decline. “In my case, no one was listening to me when I tried to tell the doctors and nurses that Josie didn’t look right to me,” said King.

Sorrel and Tony were stunned to come face-to-face with the dark side of American health care: medical errors. According to federal estimates, every year as many as 98,000 patients die from medical errors in U.S. hospitals alone. Many more are harmed.

If Josie’s death was typical of those caused by medical errors, what happened afterwards was anything but ordinary. Hopkins immediately approached the family and apologized for the death of Josie, pledging to figure out what went wrong and share its findings with the family. And after the Kings agreed to a legal settlement with the hospital, they started their own patient safety foundation named after Josie. The foundation provides funding to a variety of patient safety activities and
operates a Web site where health care professionals and the general public can learn more about preventing medical errors.

The Kings also donated a portion of the settlement back to the hospital that had killed their daughter, to make sure that what happened to Josie would never happen again. Because of this partnership, Sorrel was invited to speak at an Institute of Healthcare Improvement (IHI) meeting. IHI is one of the leading patient safety organizations, whose meetings and conferences bring together health care professionals from around the country and the world.

“I remember Dr. Peter Pronovost, one of the Hopkins’ doctors we were working with saying ‘there will be thousands of doctors and nurses there who should hear your story’. I wanted to get into their hearts, wake them up and rattle their cages,” King said.

At IHI’s 2004 National Forum, Sorrel suggested to an audience of 5,000 health care providers that parents be allowed to call in emergency medical teams when they feel their child is in danger in a hospital. Thanks to her idea, a program called Condition H (H for help) was created in two hospitals in Pittsburgh. “This program creates a team including a doctor, nurse, patient safety person and a respiratory therapist. If, for example, a parent is concerned because they sense their child is not doing well, the parent can call the entire team in and explain their concern before a tragedy occurs. If I had been able to activate a Condition H team, I believe Josie would still be alive. I know a lot of families whose children have died from medical errors and I believe the same for them,” she said.

Across Johns Hopkins, safety has now been elevated to a top priority and programs similar to Condition H are being evaluated and implemented. Every week, hospital executives walk the halls of the institution talking to front-line workers about safety concerns. No longer are workers discouraged from reporting errors or from questioning their superiors when concerned about patient care.

“Sixty percent of all medical errors are due to a failure to communicate. Doctors and nurses need to communicate with the family. They need to listen and work as a team. When I saw Josie taking a turn I said, ‘Come look at her. What’s going on? I don’t feel right.’ They listened, but I don’t think they really heard my concern for my daughter. That’s now changing,” said King.