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A MOTHER'S PROMISE

# How medical errors took a little girl's life

Tragedy: After being scalded in a bathtub accident, 18-month-old Josie King was recovering at Johns Hopkins. Then something went terribly wrong.

**By Erika Niedowski**
**Sun Staff**
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*First of two parts*

During those frightening first days in the hospital, Sorrel King came to trust the doctors and nurses looking after her 18-month- old daughter. Hooked up to tubes and machines, sterile dressings covering her burns, Josie looked nothing like the little girl who danced through life wearing ladybug shoes and a gap-toothed grin.

The medical team at the Johns Hopkins Children's Center constantly monitored Josie's mixture of drugs, watched for signs of infection, performed skin grafts to repair the damage from her bathtub accident.

If she fussed, someone would immediately check whether she was in pain. After she struggled to fill her lungs with air, a ventilator regulated her every breath. Sorrel, keeping vigil in the intensive-care unit, allowed herself to feel relief at seeing her daughter slowly heal.

As the long days settled into a routine, Sorrel began to view the doctors and nurses not just as caregivers in white coats and scrubs but as people like her, with vibrant lives waiting outside the hospital. The attending physician was Greek and loved to cook. The critical-care doctor was a new father. The pretty pediatric surgeon, a prodigy who had graduated from medical school at age 19, had a long-distance romance. Sorrel

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thanked them with brownies and fruit baskets and her admiration.

"They were the best," she said. "I loved that place."

Then, after doctors said Josie would soon return to the brother and sisters coloring "Welcome Home" cards, the little girl died. It was the most awful of deaths -- one that could have been prevented.

She had become severely dehydrated, causing her heart to stop. Because of what Hopkins acknowledges was a series of errors, the staff had missed the warning signs.

When she died nearly three years ago, Josephine Abby King became a victim of an epidemic her parents never imagined when she was admitted to Hopkins. A model in medicine, it was the hospital of last resort for some of the world's sickest patients, an institution whose doctors weren't only the very best but who trained the next generation of the very best.

"It never would have occurred to me that they would make a mistake," said Sorrel, 38. "I never knew that a hospital could be a dangerous place."

Between 44,000 and 98,000 patients die -- and countless others are harmed -- from medical errors in U.S. hospitals every year, according to a landmark report by the Institute of Medicine, a government advisory panel. Even the lower estimate, the 1999 report noted, is more than the number of annual deaths in the United States from motor vehicle accidents, breast cancer or AIDS.

The errors range from medication overdoses to surgeries performed on the wrong body part to X-rays read backward. In most cases, patients aren't injured as a result of a single mistake by a doctor or nurse but from a cascade of failures in a system without enough safeguards.

The results can be tragic. A man scheduled for a spinal scan at a Maine medical center died in October after the wrong dye was injected. A woman who underwent a double mastectomy in St. Paul, Minn., later learned that she never had cancer; biopsy results had gotten mixed up.

Even the most elite hospitals are not immune. A 17-year-old girl died in February at Duke University Hospital in North Carolina after receiving a heart and lungs from a donor with an incompatible blood type. At Children's Hospital in Boston, a 5-year-old boy died last spring after his doctors failed to treat him for a seizure because each thought someone else was in charge.

In Josie's case, Hopkins had failed Sorrel and her family in the most fundamental way. They had trusted the institution, and that trust had been betrayed.

"Josie died of a Third World disease -- dehydration -- in the best hospital in the world," said Dr. Peter J. Pronovost, a Hopkins anesthesiologist who is heading that institution's effort to reduce errors. "How could that possibly happen? The answer is, we've created a system that's allowed it to happen."

## A magical adventure

An annual Christmas card photograph shows the sunny life Sorrel (pronounced Suh-RELL) and her husband, Tony, had built: Their children are perched on a ladder propped against a lifeguard chair on Martha's Vineyard, in Massachusetts. Jack, the eldest, is on top, with his light-red hair and earnest 6-year-old smile. Next are round-faced Eva, then 3, and her blond sister Relly, 5. Josie, then 1, sits on the bottom rung, her head tilted, wearing a green and purple gingham dress over her diaper.

As the youngest child, Josie held a cherished spot in the family. By the time she was 18 months old, she was somewhere between babyhood and being her own little person. She had just learned to say "I love you" and to climb onto the backyard trampoline. She was an accomplished flirt, waving hello and blowing kisses to workers building an addition on the house. Sorrel had dubbed Josie "the little wrecking ball" because she would disrupt everything she came across, dumping out drawers full of shoes, messing up her brother's Legos or breaking her father's glasses.

Josie's sense of last-child entitlement manifested itself every weekday around noon. When she heard Relly and Eva coming home from school, she would run to Sorrel and hug her legs, yelling, "Mine! Mine!" And she would insist that her parents hold her whenever she pleased.

Sorrel and Tony met in college at the University of Colorado and fell in love surrounded by ski slopes and mountain bike trails. Sorrel had given up a designing career to take care of the kids while Tony worked a fast-paced job trading stocks for Wachovia Securities. They were naturals as parents, and resilient, too. They were unfazed by food on the floor, toys littering the dining room or a dog desperately in need of a bath. Their household brimmed over with life.

Before moving to Baltimore County in 1999, the Kings had lived in Richmond, Va., where Sorrel grew up. Her women's casual clothing line -- sold by such high-fashion stores as Barney's and Saks Fifth Avenue -- and Tony's work at First Union, now Wachovia, enabled them to buy land in the country and build the house they'd always wanted. Sorrel's parents, Jack and Sorrel McElroy, were their new neighbors; it was a 200-yard walk from door to door.

Then First Union asked Tony to help set up a new trading desk in Baltimore. As wrenching as it was to leave, the Kings viewed the move as an adventure. The couple bought another house, once a barn, atop a grassy hill off Falls Road. It was like their own patch of country, albeit with a Starbucks down the street.

## The accident

The night of the accident, Jan. 30, 2001, Sorrel bathed the children in a bathroom the family seldom used. Sorrel's mother, visiting from Richmond, had taken a bath there and the children were excited by the novelty. Before bedtime, the family watched cartoons in front of the fire. Josie played with a musical toy, dancing a silly dance that made her knees buckle. After a while, following Relly, she wandered upstairs.

Her screams sent Sorrel running up the steps. Josie was in the bathroom again, her washcloth and toy airplane in the tub, her pink pajamas soaked. She had turned on the water and climbed in, scalding more than half her body before scrambling out. Sorrel yelled for Tony to call 911, then ripped off the pajamas, wrapped Josie in a towel and waited anxiously for help.

An ambulance took her to Johns Hopkins Bayview Medical Center, which specializes in treating burns, but she was soon transferred to the pediatric intensive-care unit at the Hopkins Children's Center.

The 16-bed unit was a somber place, stressful for parents, families and physicians. The young patients had undergone complex surgeries or were being treated for crash injuries or gunshot wounds, grim reminders of Baltimore's street violence. Tubes and wires hung every which way, and sophisticated equipment flanked every bed. The cramped intensive-care unit offered little privacy. It was utterly foreign to Sorrel, whose only experience in a hospital had been to give birth.

She stayed by Josie's bedside day and night, often in the first few days with Tony, then later with her mother or younger sister, Margaret Reitano, who would drive up from Washington. Sorrel studied books from the library about burns. She discussed unfamiliar procedures with the doctors. She assisted anyone who would let her with the daily routine.

Whatever sleep Sorrel allowed herself came on a narrow folding chair in the Children's Center "family room," where she could also shower and brush her teeth. Occasionally, she would leave the hospital to go for a run, but not for long.

"We saw more of each other than married couples," said Dr. Milissa McKee, a pediatric surgical fellow. Dr. Amal Murarka, an intensive-care specialist, worried that Sorrel wasn't taking care of herself and urged her to go home; her other children missed her. But Sorrel blamed herself for Josie's accident and wanted to be at the hospital to offer a mother's comfort.

Sorrel and Margaret relied most on the doctor in charge of Josie's care, Charles N. Paidas, director of pediatric trauma, whose patients were among the smallest and most vulnerable in the hospital. When he was in sterile gloves changing Josie's burn dressings, Paidas would sometimes ask one of the sisters to dig his ringing cell phone out of his coat pocket and hold it to his ear. Margaret teased that he reminded her of the Greek

doctor in the novel Corelli's Mandolin, so Sorrel bought him a copy and inscribed it in Josie's name. She talked to Paidas, who enjoyed cooking, about a chili cook-off to raise money for the trauma unit.

Paidas' surname came from the Greek word for "young child" and suggested his calling as a pediatric surgeon. Intense and purposeful, he tried to care for his patients as he would his three children.

"I always felt safe when he was around," Sorrel said.

## An anxious beginning

It seems like a contradiction, but had Josie suffered more-severe burns, she might have been in less pain. As it was, she was being treated for second-degree burns over 60 percent of her body, including her arms and legs, her face and fingers, her chest, back and feet.

First-degree burns, such as sunburn, injure the outer layer of the skin, the epidermis, and usually heal in a few days. Second-degree burns go deeper and usually cause swelling, blistering and intense pain. Third-degree burns, which can be disfiguring, go deeper still. They can be terribly painful, but if the nerve roots have been destroyed, there may be no pain at all.

Burns can be deadly because the skin may not be able to perform its most important functions: protect against infection, control body temperature and prevent loss of fluid.

Young children are particularly at risk because of the potential for dehydration. They need to take in relatively more water than older children and adults; their higher amount of surface area compared to body mass means they lose more fluid through the skin. Injuries and infections compound normal fluid loss and can lead to life-threatening imbalances of water and electrolytes, which help regulate nerve and muscle function.

It was essential for Josie to receive intravenous fluids, but finding the veins in her burned limbs had proved difficult. Physicians at Bayview put a line in the marrow of her leg bone, a procedure of last resort.

At the Children's Center, doctors managed to place IVs in Josie's neck and wrist and, later, in her femoral vein, which runs up the inner thigh. In the operating room a few days later, the medical team inserted a so-called central line into a large vein under her collarbone so the staff could administer drugs and draw blood without constantly having to stick her with needles.

The first few days were difficult. Josie was attached to a ventilator because she couldn't breathe on her own. To ward off infection, doctors removed dead tissue and changed her sterile dressings at least twice a day, either at her bedside while she was sedated or in the operating room under anesthesia. They performed skin grafts, transplanting skin from other parts of Josie's body and from a donor.

But Josie's breathing tube was soon removed and her burns started to heal. Sorrel recorded as miniature milestones things that wouldn't have had much meaning before: Josie eating Jell-O, Josie drinking ginger ale, Josie getting a shampoo. The possibility of taking her daughter home in a week or 10 days made her hopeful.

"All I can do is just stare at her," Sorrel wrote in notes she took at the hospital. "We just sit there and stare at each other. It is like we both know what could have happened and all that we do or say is just look into each other's eyes. It is like she understands how lucky she is to be here."

Just before Valentine's Day, after nearly two weeks at Hopkins, Josie was well enough to be transferred one floor down to the intermediate-care unit. Sorrel worried aloud about the switch to a less-intensive setting where she didn't know the nurses but was assured that everything would be all right. Paidas and other doctors she knew would still oversee Josie's care.

At home, Jack, Relly and Eva were getting ready for their sister's homecoming, blowing up balloons and making colorful cards. "Welcome home Josie and Mom," said one, with a picture of two smiling yellow balloons and an orange-headed turtle.

Sorrel had plans, too. She intended to paint Josie's room, put in a new bed and curtains, and throw a party to thank everyone who had helped the family through the ordeal. She would hold it in the spring or early summer, and she would invite family and friends and the Hopkins doctors and nurses who had healed her little girl.

"I think the day I bring her home will be the happiest day of my life," she wrote.

## A desperate thirst

Sorrel was the first to notice her daughter's desperate thirst. Whenever Josie saw a drink, she would whimper or even scream for it. One day, after a trip in her stroller down to the playroom at the end of the hall, Josie reached frantically for the water she saw her grandmother sipping through a straw. She could speak just a few words, but it was obvious what she wanted.

Sorrel and her mother tried giving her some fluids -- a nurse seemed uncertain whether water, diluted juice or ice chips would be best -- but Josie spit them up. The nurse advised Sorrel not to give her anything more.

As with any patient, Josie's caregivers relied on a basic inventory of objective measures to help determine how well she was doing. They checked her heart and respiratory rates, blood pressure, temperature and, because she was a pediatric patient, body weight, a good measure of hydration. Nurses also recorded what are known as "ins and outs." The

"ins" included intravenous fluids and food and drink taken by mouth or through a tube; the "outs" included urine and stool, chest tube drainage and any vomit. Josie's blood was drawn regularly to check for infections or other problems. The medical records generated during her three-week stay could have filled a footlocker.

But lab reports and test results can't tell a doctor everything. Patients know better than anyone how they're feeling, and physicians rely on them to describe their symptoms and explain, for instance, how much pain they're in or how soundly they slept. With young patients like Josie who can't communicate well, input from parents is essential.

Each scrap of information by itself may not reveal much, but together they form a picture of sickness or health. The challenge of modern medicine is making sense of all the data that pours in and ensuring that nothing critical gets overlooked in the bustle.

Josie's burns continued to heal; her skin was responding well to the grafts. After her final trip to the operating room for dressing changes, the pump that delivered pain medication was removed. The child was started on methadone to wean her body from the powerful drugs she had been taking and to prevent withdrawal, which could cause diarrhea and increase heart rate and blood pressure. The methadone would also relieve pain during bedside dressing changes.

Despite the good news, some problems developed during Josie's first days in the new unit. She was vomiting and suffered intermittent diarrhea. She also had occasional fevers -- a sign of infection -- though blood, urine and stool cultures all came back negative.

On Feb. 18, Josie's temperature rose to 102; the next day, a blood culture confirmed the presence of bacteria, though not which type. Doctors started Josie on intravenous antibiotics.

It wasn't enough just to treat the infection; they had to identify its source. As physicians do every day, they weighed the data and made an educated guess. The problem, they figured, was Josie's central line, which can harbor bacteria.

Paidas removed it and put her on an oral antibiotic. For the first time since entering the hospital, she had no IV line to deliver drugs and fluids. Without a tube protruding from Josie's chest, Sorrel could finally hold her. She felt a step closer to getting her daughter back.

During her bath that night, Josie was weak and Sorrel had to prop her up. The child was sucking furiously on the washcloth, which Sorrel thought strange. By bedtime, Josie's eyes were rolling back in her head.

Alarmed, Sorrel found a nurse and asked her to call a doctor. Checking Josie's vital signs on the overhead monitor, the nurse told her they were normal. When Sorrel asked that someone else look at her daughter, a second nurse offered the same reassurance.

Reluctantly, Sorrel went home to get some rest and to see Tony, who was flying to the West Coast the next morning on business. He would be home in time to celebrate Josie's homecoming.

Sorrel called the hospital twice during the night and was back at Hopkins around 5:30 a.m. After taking one look at her daughter, she ran into the hall.

"Please come look at Josie!" she pleaded to McKee and other doctors on morning rounds.

Josie was lethargic and pale, her eyes sunken and dilated. She wasn't moving her arms or legs or responding to commands. Her blood pressure was slightly low. Worried that she might have been oversedated with methadone, doctors ordered a shot of Narcan, which is used to reverse narcotic-induced depression or an overdose. Within 20 minutes, she was more alert.

Sorrel told the doctors Josie was thirsty and asked if she could give her something to drink. Josie greedily downed more than 20 ounces, or almost two soda cans, of juice through a straw. "Mo," she kept saying -- her toddler version of "more." About an hour later, she was given another shot of Narcan. No one seemed sure what had caused her condition to deteriorate.

Paidas, summoned by a worried McKee, ordered that Josie be given no more narcotics unless he or another surgeon was consulted; he wanted to see how she would do without them. Sorrel was relieved. The medications had always made her uneasy. When Josie was in the intensive-care unit, she had noticed that rubbing her daughter's head would often help soothe her, and she had asked the nurses to try that before administering more drugs.

That morning, Josie kept all her fluids down. She was looking around the room, watching Scooby Doo cartoons on the overhead TV and eyeing the alphabet chart on the wall. Sorrel, still anxious, repeatedly asked the doctors to stay nearby.

About 11:30 a.m., a pediatric anesthesiologist stopped in. Though Paidas directed Josie's care because she was a surgical patient, she had also been treated throughout her stay by the "pain team," which oversees the use of narcotics. Dr. Sabine Kost-Byerly, who was heading the team that day, was concerned that Josie would experience withdrawal symptoms unless she got some methadone. The morning dose had been skipped.

Paidas was in the operating room, so Kost-Byerly checked with other surgeons, as is customary practice. She and McKee agreed that a lower dose of methadone should be given.

About 1 o'clock, the nurse on duty came in with a syringe.

"What are you doing?" Sorrel asked. She told the nurse that Paidas had

said Josie was not to get any narcotics. The nurse replied that the order had been changed, and gave the child the medicine.

Not long afterward, Josie's heart stopped while Sorrel was rubbing her feet. By the time the doctors could restart it, the damage had been done.

## Letting go

There would be no miracle. Later that night in the ICU, where Josie was again hooked up to tubes and machines, Sorrel begged God to save her child. But, the next day, after running all their tests, doctors explained that Josie had suffered devastating brain damage as a result of cardiac arrest.

Sorrel and Tony had been preparing to bring their daughter home from the hospital; now, in a haze of shock and sorrow, they were going to have to prepare to let her go.

They had her christened at a bedside ceremony performed by a minister and family friend, Thomas G. Speers. They had Sorrel's mother bring Jack, Relly and Eva to the hospital, where a counselor gently told them what to expect. Then Sorrel and Tony led the children into Josie's room, where they kissed their little sister goodbye.

Her crash had been sudden. On the day Josie's heart stopped, Murarka, the intensive-care specialist, had heard the call for a "code" -- a cardiac arrest -- on the overhead speaker and rushed downstairs to find several shocked staff members standing beside a patient. He didn't recognize the child in the bed or Sorrel in the corner. It wasn't until someone began a brief history that he realized whose life he was trying to save.

Sorrel was shuttled away to a room with a chaplain while doctors tried to revive Josie. She wasn't breathing and had no pulse. As Murarka called out orders, someone started chest compressions, pushing against Josie's tiny ribcage to simulate the heart pumping blood. The team scrambled to hook up a monitor, which showed that her heart was not beating. The child had vomited after an oxygen mask was placed on her, so Murarka inserted a breathing tube down her windpipe.

It was critical to get fluids and medicines into Josie immediately, but doctors couldn't get an IV into her arm or leg veins because of her burns and she no longer had a central line. They drove a small needle into the marrow of her shinbone, the same emergency procedure used soon after her bathtub accident. Increasingly desperate after the first resuscitation attempts failed, Murarka called for other doctors to assist.

Paidas and McKee rushed in from surgery. McKee placed an IV in Josie's groin. The rest of the team pumped rounds of drugs and fluids into her body.

It had been 15 minutes or more. Josie still wasn't responding.

"This is not happening," Murarka said. "I can't believe that this child is

going to die right here."

And then she came back.

## A system overwhelmed

When Sorrel saw Josie again, more than an hour later, she had been moved to the intensive-care unit. She would spend her last 48 hours on life support. Margaret was grateful that she -- and not her sister Sorrel -- was standing at the head of Josie's bed when doctors examined the little girl's vacant eyes.

"It was just something that a mother of a child should never have to see," she recalled.

The human body, while amazingly resilient, can tolerate only so many insults. In retrospect, it was clear that Josie's system was overwhelmed. Though Sorrel had expressed concerns about Josie's symptoms and crucial data had been recorded on the charts, no one had pieced together that information and realized that she was in peril.

The day before her heart stopped, Josie's weight had dropped precipitously -- nearly 20 percent -- in itself a life-threatening emergency. Her diarrhea had become so severe that she soiled her diaper 14 times in 24 hours. Josie had become so dehydrated that her body began to shut down.

In its mildest form, dehydration is easily treated by administering fluids, usually by mouth. Moderate dehydration also can be treated successfully, often with intravenous fluids.

But severe dehydration can lead to seizures, brain damage or death. It can significantly reduce blood volume and cause blood pressure to drop so much that the blood can't deliver oxygen and vital nutrients to the heart, brain and other organs. Past a certain point, there is no correcting the harm it does, even with a massive infusion of fluids.

Paidas would say later that the critical time for Josie was the 12 hours before her heart stopped. It is unclear how much fluid would have been needed to reverse her downward course. Paidas and McKee wonder now whether Josie's "ins and outs" had been recorded properly. The child's urine output, a sign of hydration, had been noted as adequate or better for several days. But even so, the team had missed other warning signs.

"I'm just as culpable as anyone, as the captain of the ship," Paidas said. "There is something that eats away at every physician who took care of her."

What role, if any, the methadone played is unclear. Hopkins contends that Josie's cardiac arrest resulted from severe dehydration and that the narcotic was not a factor; it couldn't have been absorbed that quickly, according to Dr. George J. Dover, head of the Children's Center. Paul

Bekman, the Kings' lawyer, said that outside physicians reviewing Josie's records concluded that the methadone, which can slightly lower blood pressure, aggravated an already dire problem. No one will ever know for sure. An autopsy provided no answer; it said only that Josie had died of complications from burns.

The evening of Feb. 22, 2001, after their other children said goodbye to Josie, Sorrel and Tony did the same. They held hands while Speers read the 121st Psalm -- "I will lift up my eyes unto the hills. ... The Lord shall preserve thy going out and coming in from this time forth, and even for evermore" -- and led a round of prayers at Josie's bedside. Then Murarka gently unhooked the little girl from the machines and wrapped her in a blanket.

Sorrel and Tony took turns holding her, rocking in a rocking chair and singing songs that might, on an ordinary night, have eased her into sleep. Outside the hospital window, snowflakes drifted down, turning pink under the streetlight, and in the quiet it seemed as if the world had stopped.

At 6:11 p.m., Josie was gone.

## A family torn apart

Two days later, Margaret delivered the eulogy, which she had written while sitting in Josie's bedroom at home. She remembered her niece's gift for getting what she wanted and how she would yank on her brother Jack's hair when he wasn't paying attention to her, calling out, "Ack! Ack!"

She recalled Josie's awe over a beach plum while on vacation at Martha's Vineyard the summer before and the way she would embrace her little cousin Marlee with such force that Marlee would fall face-first in the sand.

Then she addressed Josie, whose early evening arrival in heaven, she said, had made the sky turn pink.

"Instead of putting markers on the sofa, you will color the sky," Margaret told those gathered at the Church of the Good Shepherd in Ruxton. "Instead of sandboxes, you will create beaches. Instead of banging on pots and pans, you will clap out the thunder and lightning. Instead of picking flowers, you will plant forests. Instead of knocking your siblings' building blocks, you will help in making mountains."

The church was overflowing. There were people from Richmond, Tony's co-workers from Wachovia, friends of Sorrel's mother and father from North Carolina and Seattle, parents whose sons and daughters went to school with the King children. Jack, Relly and Eva were in their Sunday best.

Among the mourners were some of Josie's nurses as well as Paidas and McKee. Physicians don't usually attend the funerals of patients; it's a

way of protecting themselves from the inevitable sadness. Paidas knew that to the Kings, the doctors represented the tragedy. But he, too, had been devastated by losing Josie, and that outweighed anything else.

Sorrel saw him and McKee at the church. Looking back on that day, she remembers her tangle of emotions, recalls the crushing grief. She didn't blame the doctors, but she couldn't accept that her daughter died needlessly in the hands of medicine's best.

She made sure that Paidas and McKee were coming back to the house after the service. She wanted them there more than anyone else.

"Those were the only people I cared about seeing," Sorrel said. "I wanted them to see the perfect family that Hopkins ruined."





A MOTHER'S PROMISE

# From tragedy, a quest for safer care

Cause: After medical mistakes led to her little girl's death, Sorrel King joined with Johns Hopkins in a campaign to spare other families such anguish.



**By Erika Niedowski**
**Sun Staff**
**Originally published December 15, 2003**

*Second of two parts*

Sorrel King seemed small up on stage next to the two photographs of her daughter Josie, projected on a huge screen. In one shot, the brown-haired girl looked like she'd been caught in mid-giggle.

Most of the speakers at this Washington conference on patient safety last March were professionals, armed with statistics and Powerpoint presentations. Sorrel arrived with a few sheets of paper filled with words written in pain. She wasn't there to share research or discuss hospital policies. She was there to talk about the loss of her child.

"I am not a doctor or a nurse, and am by no means an expert in this field," she began. "I am a mother who has seen the darkest side of a hospital."

And with that, she told the story of Josie. While recovering from burns at the Johns Hopkins Children's Center, the 18-month-old died as a result of medical error. She had become so dehydrated that her heart stopped, but the staff had missed the warning signs.

At first, consumed with anger and grief after Josie's death nearly three years ago, Sorrel had wanted nothing more than to punish the hospital.

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Playing role of reality for

"What will we do with Hopkins," she wrote in her journal. "How can they get away with this. They must suffer. They must honor her memory. They must be responsible. They must feel the pain that we feel."

Then Sorrel King did something extraordinary. With her husband, Tony, she reached out to the very institution that had failed her family. The Kings offered their money, their time and a selfless commitment to help make Hopkins a safer place. They would never get what they most wanted - their daughter back - but they hoped to spare other families their tragedy.

Sorrel found an ideal partner in Peter J. Pronovost, a Hopkins physician and patient safety expert, whose father had been the victim of a medical mistake. Together, they worked to change the hospital, she from outside its walls and he from within. They began on the two floors where Josie had been a patient. But their goal became something grander, something that had never been done. They wanted to transform the culture of America's hospitals.

That day in Washington, with Pronovost on the stage beside her, Sorrel suggested to the audience a way to accomplish that.

"Each doctor and nurse must realize that they are fallible," she said. "That they must treat each other as equal partners when it comes to a patient's safety. That they must listen to each other, listen to the patient and listen to the parent. Only then will we have a solid foundation on which to build technologies and more perfect systems."

Though medical mistakes are a leading cause of death in the United States, most hospitals are only beginning to take measures to prevent them.

"The first reaction as a physician is to say, 'This would never happen at my hospital,' or, 'We can fix this with incremental change,'" said Dr. William R. Brody, president of the Johns Hopkins University.

But protecting patients from harm will require much more. "We really need to redesign the whole system from the inside out," said Brody. "This is a revolution."

Since Josie's death, Hopkins has become a leader in improving patient safety and Sorrel one of the most visible advocates of the effort. Her story has reached thousands of people she has never met in places she has never been.

She has inspired changes that may save lives at an ICU in Connecticut, a critical care center in rural Georgia, a hospital halfway across the

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world in Singapore - and on the very floor where her daughter died.

"There's magic that's going to come out of this," said Dr. Charles N. Paidas, a pediatric surgeon at the Children's Center who directed Josie's care and became an integral part of the safety initiative named for her. "And I don't think anyone here would disagree: It's because of the family."

For Sorrel, campaigning for patient safety has been a calling she neither imagined nor wanted but whose responsibilities she fulfills with a dedication that at times surprises even her. A pharmacist at a 45-bed hospital in Nebraska recently thanked her and offered these words of advice: "Don't let the wind die down."

She doesn't intend to.

## Taking responsibility

As she travels around the country, Sorrel says that families who have lost loved ones to medical mistakes want hospitals to do three things in the aftermath: Apologize. Tell the truth. And take steps to fix the problem.

In her case, Hopkins has done all three.

On March 4, 2001, the second Sunday after Josie's death, Dr. George J. Dover visited Sorrel and Tony at their Baltimore County home.

"This is my hospital. This happened on my watch. This is my responsibility. I'll get to the bottom of it," the head of the Children's Center told them.

It was a step that might make some hospital lawyers cringe, particularly in an era of mandatory "risk management" sessions - a common topic is how to avoid getting sued - and running debate over whether the words "I'm sorry" are tantamount to an admission of wrongdoing. But Dover wasn't there to deliver lines from the legal department. He believes that you can't be a good physician if you deliver only the good news. At least a dozen times after his hospital lost patients, Dover had made home visits to their families, including one whose child died of a missed infection while under his care.

Dover told the Kings that what had happened to Josie was a "sentinel event" - an unexpected occurrence resulting in serious injury or death. He said a committee would review, as required, what had happened and recommend ways to correct any problems. He assured them that the hospital would not try to cover anything up and offered to update them regularly on the status of the review. He even blocked out time between 9:30 and 10 every Friday morning to talk to Sorrel.

Sometimes the weekly conversations seemed to do more harm than good, Dover thought, compounding Sorrel's grief by making her relive the tragedy.

"There was nothing that I could say or do - nothing the hospital could do - that would compensate in any way for what had happened," said the 56-year-old specialist in pediatric oncology and hematology. "But somebody, I think, at least needed to listen."

Tony had gone back to work trading stocks at Wachovia Securities soon after his daughter's death; he dealt with his grief more privately, and resuming his daily routine helped. Sorrel's sorrow, by contrast, spilled out everywhere. She spent hours in her daughter's room, rocking in the chair, looking out the window and holding a plaster cast of Josie's hand that the hospital had given her. At night, she dreamed of Josie sitting in her car seat, drinking Gatorade and getting well.

She hoped that seeing a grief therapist would help her feel better. She thought the pain would lessen as time went by. She was wrong about both things.

At times, Sorrel wondered whether the family should have stayed in Richmond, Va., where their life had been so good. And she grappled with guilt over the accident that sent her daughter to the hospital. If she had only followed Josie upstairs that January night, Sorrel thought, she could have stopped her from drawing a scalding bath and climbing in.

The house seemed utterly quiet now, even with the noise from her other three children and the construction workers finishing an addition. Her mother, observing Sorrel's despair, felt that she hadn't just lost a granddaughter but her daughter, too.

"As each day goes by I seem to be sinking deeper and deeper into this place," Sorrel wrote in her journal. "Everything seems to be slowly fading. The sun is less bright. Food has less taste. What used to make me happy brings me no enjoyment. My body is a shell and someone who I don't know is in it and does the functioning part while I am going away."

Eventually, Sorrel moved the crib from Josie's bedroom and took her bookshelves down. She laid a new rug in preparation for 4-year-old Eva to move in, though she wasn't sure it was the right thing to do. The changes troubled her son, Jack, then 7. Rather than putting Josie's clothes away, he wanted to tape them to the walls of his room.

By June 2001, four months after Josie died, Hopkins had finished its review and told Sorrel and Tony what they had known all along: Josie's death had resulted from a total breakdown of the system. Three weeks into her recovery, the child had suffered devastating brain damage after her heart stopped because of severe dehydration. The medical staff hadn't responded appropriately to the warning signs - her precipitous weight loss, severe diarrhea, intense thirst and lethargy.

"The information was there, but no one really put it all together," said Richard P. Kidwell, Hopkins' managing attorney for claims and litigation, who handled the King case.

The committee that reviewed the death saw shortcomings in communication, including between the surgeons and pain team and between doctors and nurses, according to Kidwell. He said the caregivers should have listened more closely to Sorrel, who had repeatedly expressed worries about her daughter's decline, and investigated her concerns thoroughly.

"Nobody knows a child better than the parents," he said.

According to Kidwell, the committee concluded that the temporary agency nurse tending to Josie the day her heart stopped should have been more aggressive in alerting physicians to the child's symptoms. And after doctors removed Josie's central line - a tube in her chest used to administer drugs and fluids - they should have placed another intravenous line, the panel said. Resuscitation efforts after Josie's cardiac arrest were hindered without one.

"There was a breakdown of the system at multiple levels," said Paidas, Josie's lead physician, who still keeps a prayer card with her picture in his office. "I can't honestly put it together any more than that."

Indeed, what went wrong in Josie's case is at once simple and complex. In an age when doctors can perform near-miracles, transplanting hearts and performing surgery in utero, Josie's medical team seemed to have disregarded one of the most basic teachings of medicine: Study the patient.

Healing is not just a science involving mastery of anatomy or reliance on sophisticated machines. It is also a nuanced art, best practiced by making a physical connection with the person in the bed. William Osler, a Hopkins founding father revered as one of medicine's greatest physicians, was a master diagnostician able to pick up things that others missed - simply by observing, listening to and laying his hands on the sick.

"You need to examine the patient," said Paidas. "We get comfortable relying on machines and laboratory values."

What happened to Josie also demonstrates the difficulty of managing treatment in hospitals today. Caring for just a single patient involves dozens of people: doctors, doctors-in-training, nurses, respiratory therapists, pharmacists, lab and X-ray technicians and others. Multiply that complexity by 1,000: Hopkins has nearly that many beds. Medicine is an enterprise that can succeed only with collaboration. But few who spend their lives trying to heal others, Pronovost points out, are trained in teamwork.

Even after Hopkins acknowledged responsibility for Josie's death, Sorrel struggled with how to respond. One option was to file a lawsuit, which would have drawn national attention and tarnished Hopkins' reputation.

But the hospital had offered to settle the case out of court, and Sorrel's family believed that course would be easier on her than a protracted legal battle. The Kings' lawyer, Paul Bekman, began talks with Hopkins, even though the idea of accepting money for Josie's life disgusted Sorrel.

Some days, she couldn't contain her anger. On what would have been Josie's second birthday - July 1, 2001 - she phoned Dr. Amal Murarka, one of Josie's doctors, and told him that she should have been putting two candles in her little girl's cake. She told her lawyer she wanted to call a newspaper. She vented to her husband.

"She was so angry that she just wanted to do whatever she could to bring down Hopkins," Tony said.

Gradually, though, Sorrel and Tony reached a conclusion: Something good had to come from their family's suffering. Sorrel remembered a pledge she had made four days after her daughter's death.

"I will do something great for you, Josie," she had written in her journal. "Please help me find out what that is."

That something great, the Kings decided, would be to help make Hopkins a safer institution. Perhaps other hospitals, which view the Baltimore medical center as a model, would change too.

"I realized the huge reputation that Hopkins has: It's the best hospital in the world," Sorrel said. "I also realized they would listen to me."

They reached a settlement with the hospital in August 2001 for an amount neither party will disclose. The Kings planned to put some of the money back into the Children's Center. Signing the papers didn't mark an end; it marked a beginning.

"The kind of anguish and bitterness that they were entitled to can consume you," said Dr. David M. Cromwell, a Hopkins gastroenterologist and family friend. "And they worked through that, which was probably the first small miracle in this story."

## In Josie's memory

Sorrel didn't want to memorialize her daughter with a garden or a statue or an annual lecture in Josie's name. She wanted nothing short of changing the hospital. And, as it turned out, Hopkins' point man on patient safety already was trying to do just that.

Sorrel met Pronovost a short time after the settlement. It was an obvious match, but no one had thought of it until Cromwell heard the physician speak at a mandatory risk management meeting. Often, Cromwell said, such sessions involved lawyers talking about what to do after something had gone wrong. Instead, here was a doctor talking about ways to prevent problems.

Pronovost called Sorrel and told her about his research. He met her and Tony at their house. When Sorrel showed him pictures of Josie, he cried. She looked a lot like his own daughter. "It could have been her," he thought.

The 38-year-old anesthesiologist and critical care specialist had an unusual passion about preventing medical mistakes. Sorrel soon found out why: When he was a fourth-year medical student at Hopkins, his father died as the result of an error made at a Connecticut hospital. His father's lymphoma had been misdiagnosed as another cancer and, for years, he did not receive proper treatment. He died at home, writhing in pain, weighing only 80 pounds.

"Sorrel and I both felt this very strong commitment that patients deserve more," said Pronovost. "I think that really kind of solidified our bond. We felt like kindred spirits, that we were on a mission together."

Sorrel realized she had found a partner.

"I was drawn to him because I had not met anyone - any doctor or anyone ever - that understood what we were going through," she said.

Pronovost was candid about the mistakes and near-misses he had seen in his own institution. He had once removed a breathing tube from a woman who, it turned out, couldn't breathe on her own, and suffered brain damage. She eventually recovered, but the experience shook him.

It would take almost a year to arrange the details of the Josie King Patient Safety Program. Funded in part by an initial $50,000 contribution from the Kings, the effort consisted of two teams at the Children's Center that would identify safety problems and devise ways to prevent them.

Launching the program in September 2002, Pronovost introduced Sorrel at a pediatric grand rounds in Hopkins' Hurd Hall. It was standing room only; the auditorium was packed with doctors, nurses, pharmacists, even the hospital president, Dr. Edward D. Miller. Tony was in front, while a few friends sat farther back with Sorrel's parents and sisters, Mary Earle and Margaret. Beside Margaret was Paidas, who had proudly said yes when Sorrel asked him to participate.

Just being in the hospital again was draining. But Sorrel knew that the people she was about to address were the very ones who could lead the way in making medical care safer.

"Hospital errors are a man-made epidemic," she told them. "Doctors and nurses make mistakes, and lives are being lost. These human errors need a human solution. You are the only ones that can solve this problem," she said.

"I have known I would one day find the strength to share this story with you," Sorrel continued. "My precious memories and everlasting love for Josie give me this strength, and I will not rest until we make something

good come out of her senseless death. I am not asking for your pity. I am asking for your help."

Losing Josie had changed Sorrel's life, but her speech that day altered it once more. Over the next 15 months, in between carpools and spinning class and taking her new son, Sam, to music, she would tell her story over and over, often with Pronovost at her side.

She has traveled to medical conferences in Boston and New Orleans, Washington and Chicago, and been invited to speak in Mexico and the Netherlands. She has addressed medical students at Hopkins and launched a Web site, josieking.org. She has shipped more than 100 videotapes of her speech all over the world; a doctor in Jerusalem even translated her story into Hebrew.

The Kings have funneled more of the settlement money to Hopkins and raised an additional $200,000. Large and small, the contributions have come from family and friends, colleagues and strangers. Sorrel's brother ran a marathon in Josie's name in April, collecting more than $1,000 a mile in donations.

Sorrel has been working with Hopkins to make safety as much a part of the curriculum at the medical and nursing schools as basic science, and her brother-in-law, Jay King, has created a Web-based patient safety program with Pronovost. Hopkins plans to test the initiative soon, and Sorrel and Tony hope hospitals across the country will one day use it.

"We're just really getting started here," Tony said.

It has taken a long time, Sorrel says, to build relationships with people at Hopkins and convince them that her intentions are good. She says she doesn't blame anyone for Josie's death; she blames a flawed system.

"It's not about me hating hospitals or people like me hating hospitals," she says. "The bottom line is, the hospitals want help."

Those who know Sorrel credit her with spurring others to improve their institutions. "There are certain people in this world that are mentors, that spark enthusiasm, new energies in people," said Paidas. "And Sorrel's that kind of person."

Hopkins leaders say their hospital is different now because of Josie's death and her mother's campaign. "That was one of the most important catalysts to move us forward to try to change the culture of safety," said Dr. Beryl Rosenstein, vice president of medical affairs.

He and others at Hopkins acknowledge that change comes slowly and that their work is far from done. "My expectation is that no child should die from a preventable cause in the Children's Center or any hospital," said George Dover, the pediatric center chief. "I don't think we'll ever reach perfection, but that ought to be our goal."

## Harm-free care

When Hopkins launched its review of Josie's death, Dover wasn't looking for someone to blame. He was looking for deficiencies in the hospital's system that had allowed failures to align.

Though there are, of course, caregivers whose mistakes are theirs alone, the fundamental premise of the safety movement is that people don't fail - systems do. Patients are almost always injured not as a result of a single lapse, but when a series of them occur. The aim, then, is to anticipate mistakes and build in enough safeguards to insulate patients from harm.

"Fallibility is part of the human condition," said Pronovost. "Our goal is going to be to make care harm-free. It is not going to be to make care error-free."

Other industries in which mistakes can take lives, including aviation and chemical manufacturing, have taken leaps in improving safety, in part by adopting this principle: All injuries are preventable. Those industries enforce standards, require that accidents be reported and investigate why errors occur and how to prevent them.

Anesthesiologists pioneered those ideas in medicine by standardizing equipment and setting guidelines - including pre-anesthesia checklists much like those that pilots use before takeoff. As a result, the mortality rate from anesthesia use has plummeted over two decades.

But broader change has yet to take hold in U.S. hospitals, even after the Institute of Medicine, a government advisory group, estimated in 1999 that 44,000 to 98,000 people die from medical mistakes every year. Experts say errors - many of them unacknowledged to patients - continue to be tolerated in hospitals every day.

"We're constantly working in broken systems," Pronovost said.

Repairing those systems requires identifying the underlying problems - and that can't happen unless people speak up. Hospitals need to create a climate where fallibility isn't treated as an offense, Pronovost and others said. Until then, doctors and nurses may still hide mistakes for fear they'll be fired or sued.

"In our industry, the first questions are, 'Who did this?' and, 'Why did they do this wrong thing?'" said Dr. Donald M. Berwick, president of the Institute for Healthcare Improvement and a pediatrician at Boston Children's Hospital. "We have cultures of secrecy and hiding and blame."

Hospitals must also convince caregivers that there can be no hierarchy when it comes to safety. The patient or worried parent should be heard. And the voice of the nurse, the resident, the pharmacist and the technician must be as welcome as that of the most highly skilled surgeon.

"I want everybody in the hospital empowered to be able to pull a cord and stop the assembly line when they see something unsafe," Brody said.

However incrementally, the push for change has begun. With no federal agency regulating hospitals, nearly half the states now require that hospitals report "adverse events" - injuries, including those caused by errors, resulting from medical treatment. Maryland will do so beginning next month. The goal is that regulators investigate incidents, identify patterns of mistakes and require hospitals to take corrective action.

Hopkins, in a safety initiative launched before the Josie King program, is trying to change practices everywhere in the hospital, from the emergency room to the pharmacies to the president's office.

Medication errors are the most common type of mistakes in hospitals. Seven percent of patients are affected, and nearly all intensive-care patients, according to Pronovost. From the time a Hopkins doctor writes an order to the point where a patient takes the medicine are more than 100 steps - each an opportunity for error.

When Hopkins finishes phasing in a new computerized ordering system, physicians will be able to put prescriptions - 3,000 daily at Hopkins - directly into the computer, rather than have pharmacists decipher and enter them. If a doctor orders an incorrect dosage or a drug to which a patient is allergic, the system - loaded with key data about that patient - will reject it. In addition, Hopkins has required more stringent checking of medications. Before giving patients insulin and chemotherapy drugs, for example, two nurses must independently verify that the dosage, schedule and method of delivery are correct.

Hopkins is also trying to reduce hospital-acquired infections, which result in about 88,000 deaths a year nationwide. If staff members fail to wash their hands or affix a surgical drape properly, they can pass on bacteria to patients. Faced with what Pronovost called an "embarrassingly high" infection rate in patients getting catheters, Hopkins instituted a simple safety checklist for doctors; nurses are to call off the procedure if any steps are skipped. The infection rate has dropped as a result.

At the same time, Hopkins has revolutionized the age-old practice of rounds. Instead of including only attending physicians and residents, they now involve nurses, respiratory therapists, pharmacists and others in some units. The group uses a printed form that prompts them to discuss safety risks, among other issues. The sheet, which has been adopted in hundreds of hospital intensive-care units, hasn't just improved communications; it has reduced complications and helped cut in half the average length of stay.

To demonstrate the hospital's commitment to safety, Brody, medical school dean Edward Miller and other hospital executives each have adopted an ICU. They stop by the units each month, asking about potential hazards. On one visit, a staff member told Miller that the unit

didn't have a needed pacemaker. One arrived the next day.

The Children's Center made several changes recommended by the panel that reviewed Josie's death. A pediatrician now joins the team of doctors caring for surgical patients. Staff members collaborate closely with the specialists at Johns Hopkins Bayview Medical Center in treating burn victims like Josie. Beds have been added to the pediatric ICU to accommodate more children.

The center has taken other steps to protect its young patients. The Josie King teams have addressed everything from missing identification bracelets to incomplete patient admission forms to outdated "drug cards." If a child's heart stops, the bedside cards help doctors know immediately what dosages of medicines to give. After 5 percent of cards in the pediatric ICU were found to contain errors, the unit began using a computer to generate them.

Experts believe it is possible to eliminate the vast majority of injuries to patients, which would save at least 100 lives a day in the United States. But fulfilling that central tenet of medicine - "Do no harm" - will take a radical shift.

"Cultural change does not occur by turning a switch," said Miller. "It's something you decide is going to be one of the top priorities of the institution, and that's what we have taken on."

## Looking forward

With their youngest son, Sam, less than a month into his "terrible twos," the Kings are again a family of six. Life is filled with soccer games and science projects and spaghetti dinners. It is different for all of them without Josie, but Sorrel can be happy again, a feeling she once thought would never return.

For the first time since Josie's death, Sorrel had fun this fall trick-or-treating with the children, who dressed as a lacrosse player and a devil, Batman and a bumblebee. And rather than dreading Christmas, she is almost as eager as her children. Finally, the joys of the holidays - hanging stockings, making gingerbread houses, watching The Sound of Music - will not be forced.

There are days, of course, when the pain of missing Josie still makes Sorrel ache. For Eva's sixth birthday, in June, she asked for Josie to come back. When Sorrel told her that couldn't happen, Eva protested: "All birthday wishes come true."

Along the way, Sorrel has questioned whether her partnership with Hopkins has demanded too much.

"I want all of you to know it has been hard to do the right thing," she wrote to Dover and others last Christmas Eve. "I want you to know that every time I walk into your hospital I have to concentrate very hard so that I don't break down into a heap of sobbing tears.

"There are days when I ask myself: Should I walk away from this hospital and close the doors? ... Should I continue to work so hard when it is so painful? Why am I giving so much to the very hospital that took Josie from me?"

Now, as she sits at her computer in a nook where her children's pictures brighten the wall, she reads the messages that remind her of the need to continue her work. Doctors and nurses share details about their patient safety projects. They ask for guidance, offer help. One Friday night last winter, a nurse from Texas who had learned of Josie's story called just to hear Sorrel's voice.

She still dreads getting up before audiences. And she hates leaving her family to hop on a plane.

But that promise she made to her daughter - I will do something great for you, Josie - is one she means to keep.



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