



John Laurence Adams

My wife of 25 years was having difficulty breathing due to related medical issues. She was being prepped for a tracheostomy when she was asphyxiated by a blockage in the anesthesiology equipment. It was later determined that an IV cap had lodged in a critical connection. The hospital staff suspected tampering and called a Philadelphia police detective.

My family and I were kept waiting for over 5 hours for more information, but the staff was told by Risk Management to avoid us. So even though we were aware of the error, the hospital still chose to deny and defend. We had to engage a major law firm to get any response.

At a final meeting after the settlement, the CMO told me he wanted to call me soon after the incident to let me know of the changes in procedure they had made, but was again blocked by Risk Management. He also admitted that the changes were only within their system.



Teresa Gentry

My interest in working towards transparency, apology and resolution when harm occurs, began after my husband suffered a catastrophic injury in 2013 when he became a quadriplegic as the result of a medical error during surgery to repair 2 bulging discs in his neck. What happened next is unusual in US healthcare. The surgeon involved and the Medstar healthcare system immediately disclosed what had happened during surgery. They apologized, took responsibility for the harm and continued communication with us to ensure our needs were met during months of rehabilitation and our adjustment to the new realities of our life. We are in contact to this day.

As a result of the honest, transparent and compassionate response we received, I have become a national advocate along with my husband, to educate others about our positive experience, and to change the way healthcare responds to harm. When providers do not accept their responsibility, then families carry the guilt, when in fact, they have done nothing wrong. Sometimes the answer is as simple as "Do the right thing."



Jeff Goldenberg, MD

My daughter, Talia Goldenberg, died from preventable medical errors. Her death lays heavily on me as I am a physician who tried and failed to get the hospital to properly take care of my daughter's medical needs. I was there every step of the way yet could not get her providers to believe she was in grave danger or take action on her behalf. Instead, I watched my daughter suffocate before my eyes, with abject fear in hers. In the aftermath of Talia's death, I was no longer able to continue my practice as a family doctor—a career I had enjoyed for over 25 years. Instead, I founded a non-profit with my wife, Talia's Voice: Projects for Patient Safety, to address communication failures in medicine. After hearing Michelle Mello speak and then meeting Dr. Tom Gallagher, I got involved with Communication and Resolution Programs. CRPs are a model of how hospitals and providers can and should respond ethically after they commit errors. Hospitals would be safer places if CRPs were standard practice, and patients and families would not experience the unnecessary "second harm" I live with daily on account of the silence we have been met with from Talia's hospital and providers. Serving on the PFAC committee allows me to speak out to help change the system for the betterment of patients and families everywhere.



Gail Handley

In 2004, I traveled from Toronto to the University of Michigan Hospital to have their star neurosurgeon remove a small brain tumor. Instead, the tumor was left fully intact while most of my healthy pituitary gland was removed. Within days, a life-threatening complication resulted in permanent brain damage causing both cognitive deficits and movement disorders. The pathologist caught the error, and although U-M is renowned for its model disclosure program, they failed to disclose it. They even failed to inform me that they had a program. The same omission occurred after I filed a claim; U-M arranged for me to participate in a mediation which was part of their disclosure program process — but never informed me that they had a program or that I was participating in it. In 2017, I created a website and asked other harmed patients/families if their hospital had a similar program. I was stunned to receive two dozen heart-wrenching stories about medical errors — yet not one knew whether their hospital had a disclosure-type program (including fellow committee members Naomi Kirtner and Jeff Goldenberg). Thus, began my research into what I learned was a common practice among hospitals: leaving patients in the dark about their disclosure-type program. This lack of transparency enables hospitals to hide errors that may be costly, time-consuming, or embarrassing. I'm old now, and because this custom has continued for more than two decades, it's high on my bucket list to stop it.



Carole Hemmelgarn

My passion around the CRP work stems from the loss of my nine-year-old daughter, Alyssa. She was diagnosed with Leukemia (ALL) and died ten days later from medical errors. It took the organization 3 years, seven months and 28 days to have the first honest conversation with me. To this day I still don't know exactly what transpired the last hours of her life. I want to make sure there is transparency, communication, learning, system changes, and caring for all those after harm, which encompasses the care providers, patients and families.



Sally Kerr

My 24 year old daughter, Maddy, died from being negligently discharged by the hospital with a blood pressure of 66/35 and prescribed medications known to have serious interactions causing her to stop breathing at home within 12hrs of discharge. Although brain dead, she successfully donated 4 organs and her corneas providing the gift of life and sight to others. The doctor and hospital gave no reasons for her death but our review of the hospital records showed gross inaccuracies and corrected notes made 9 days after her death. We confirmed the negligence and wrongful death with experts and filed suits so as to put it on the record but the financial and emotional costs were too much to follow through.

At our request, the hospital and doctor offered us a CRP process (their first ever) which they scheduled 2 weeks before the statute of limitations for legal action expired and insensitively during the holidays just before the anniversary of Maddy's death. They had done no investigation of her situation, offered no explanations and were unprepared for our questions ultimately cutting the process short as we pointed out their inaccuracies and asked for clarification. Their only concern was to avoid our pursuing legal action. I have since become involved as a Champion of Patient for Patient Safety and am working with CAI/CRPs to help educate other patient and families about their rights and resources. Through my learnings of such an awful CRP experience, I want to help them get the honest answers and proactive corrective actions based on their own or loved one's tragic medical error in their quest for understanding and healing.

Naomi Kirtner



My 23-year-old daughter, Talia Goldenberg, died from multiple medical errors. Communication failures at every level led directly to Talia's preventable airway occlusion; and failures in medical decision making during her code left her brain dead. I witnessed all of it. In the aftermath of Talia's death, the hospital was silent—they never took responsibility for the fact that Talia died on their watch, and they never communicated with us about their errors or their "care." When I learned about Communication and Resolution Programs, I felt relief knowing that other patients and families might not have to incur this "second harm"—that there is a way for hospitals and providers to help after they commit medical errors instead of further harming patients and families through their silence. CRPs require hospitals to take care of the patient's and family's needs; they require hospitals to be honest, accountable, compassionate; and—especially important to me—they require hospitals to thoroughly examine what went wrong and why and then make correctives so the same type of error doesn't occur in perpetuity. In this way, CRPs are really about patient safety. I am deeply invested in CRPs because they insist hospitals do the right thing. I am committed to helping hospitals elevate the patient and family voice within all aspects their CRP programs, and especially want to move hospitals to include patients and families in their Event Reviews. How can the hospital fix their mistakes if they don't even bother to ask the patient and family what happened? My goal is to see that all hospitals conducting CRPs include the patient and family in their root cause analyses.

Armando Nahum



Armando Nahum is the Co-Founder and President of Safe Care Campaign, an organization dedicated on Infection Prevention. In 2006, Armando Nahum and his wife Victoria began their work in patient advocacy and engagement by establishing Safe Care Campaign after 3 members of his family became infected in 3 different hospitals, in 3 different states in 10 months' time, culminating with the death of his son, Josh. He was 27. The Nahums have not only turned their family's tragedy into a positive tribute to their young son, but Armando's educational presentations "Hospital Associated Infections: What YOU Should Know" and "Change One Thing, Change Everything" inspire hospital administrations and frontline caregivers to remind, provoke and motivate all who work in the continuum of care of their most noble challenge and moral duty to prevent these infections that annually infect more than 1.7 million and kill more than 99,000 patients in the U.S.

Armando is a founding member of Patients for Patient Safety US (PFPS US) within the World Health Organization (WHO).



Leilani Schweitzer

Leilani Schweitzer is the PEARL Patient Liaison for Stanford Health Care. In 2005, her son Gabriel died after a series of medical errors at Stanford Children's Hospital. Since 2011, she has worked on Stanford's efforts to be transparent and learn after unexpected medical outcomes. She uses her own experience to navigate between the often insular, legal and administrative sides of medical error; and the intricate, emotional side of the patient and family experience. Her work with patients, families, care providers and attorneys has given her a unique view of the importance and complex realities of disclosure and transparency. Leilani's work has been discussed in the *New York Times*, *Wall Street Journal* and on *CNN.com*. She has been featured on the *Ted Radio Hour* and *RadioLab* podcasts. Leilani's TedX talk about the need for transparency and compassion in healthcare has been viewed more than 130,000 times.



Deahna Visscher

Deahna Visscher is a mother that lost her infant son, Grant Lars Visscher, when he was 11 days old due to an avoidable medical error. Through her patient safety journey, she has become a parent partner on the Patient Safety Committee at the hospital that he died at and has also become a member on the American Society of Parenteral and Enteral Nutrition (ASPEN) sub-committee NOVEL (seeking New Opportunities for Verification of Enteral tube Location) as well as a member of the Patient Safety Movement Foundation. After her son died, they were never invited to go through a Communication and Resolution Program (CRP). It seemed the only way to get answers and change was to sue the hospital. With her work as a parent partner with the hospital, she works with them on patient safety and transparency. When the opportunity came to have a production company video their work together for a patient safety conference the end video was prevented from being shared publicly unless the hospitals' part was removed. All their work for change and transparency had just regressed backwards. That is why she wants CRP's and transparency to be required for all. Everyone should know the truth and should be able to share it to further patient safety.