Thank you for being here today and for inviting me. I work in the health care industry in the United States, as an executive search consultant. I am much more comfortable in talking about the search process. I am also a volunteer on a number of patient safety committees with a number of organizations across the United States.

The reason I do this is because of a medical error experience in my family in the early 90’s. In early 2003, I served on an ASHRM special committee on patient safety in Chicago. The committee members encouraged that I begin to tell our story publicly – a story from the early 90’s. I am told this is a compelling story. I know there are many such unanticipated outcomes that happen. I know that life is fragile. I also know that if no one speaks up, then change is slow to happen, if at all.

I have no interest in our story being a burden on anyone, or in just constantly re-living the last 15 plus years. I share this to help others, and to encourage constructive ideas. My only goal is to help to cause positive change.
In this patient safety journey of mine, the following quote by Dwight L. Moody is personally inspiring. Perhaps it will be helpful to you as well: “I am only one, but I am one. I cannot do everything, but I can do something. And that which I can do, by the grace of God, I will do.”

I have had a number of years to think about the behaviors involved in our situation. It has been a lonely journey. It never goes away. I made a decision to become actively involved several years ago. I believe that patient safety is a human right, along with access, that we need to rebuild trust in our industry, to value each other, to place the patient at the center of all that we do, and to do that in a spirit of partnership between patients and providers. I am a strong and passionate patient advocate. There are numerous ways patients can play a role in their own safety. First of all, let me share our family story to give you an understanding of why I do what I do.

I. THIS IS WHAT HAPPENED TO DIANE FORD

Let me tell you what happened in our family. On May 1, 1991, at the age of 47, Diane Ford, my wife, went into a Chicago area hospital voluntarily, at the recommendation of her physician, for a “routine” hysterectomy, following lots of bleeding. During that surgery, her colon was cut, and the first surgery was followed by a colostomy.

Twelve hours later in her room, she over-dosed on morphine given to her through the PCA pump. A student nurse, walking by her room, heard a noise that she said sounded like an elephant snoring. The code team was called. It took over 20 minutes to intubate
her. That time frame caused a respiratory arrest, which caused permanent brain damage, specifically a short-term memory loss. Narcan was not available at the bedside, nor easily accessible at the nurses’ station, if there at all. We don’t know how or what happened – we don’t know if it was equipment malfunction, medication miscalculation, or what? We have never been given an explanation.

The colon was reversed in surgery two months later. She then discovered bowel in her vagina, because of a fistula. This fistula was caused by stray staples from the colostomy reversal. It was repaired, in a 4th surgery, three months later, in November, as it was not healing on its own. During the two months of wearing the colostomy bag, Diane basically had no idea of why she had the bag, how to clean, or how to change it – hard to do with a short-term memory loss.

When she left the hospital, the only person to give us some help was the colostomy nurse, who gave very good instructions. Not a single person in the hospital gave me a suggestion on how to take care of someone with a short-term memory loss. A psychiatrist met with her the day before she was dismissed from the hospital. Her style was gruff and intense. She said virtually nothing to me. Diane did not like her, and I understood why.

Every other contact that was made with area rehabilitation hospitals and therapists was initiated following my own research, even though I asked for help several times from her
physician. I don’t know that he ever picked up the phone to solicit counsel or referrals from anyone.

Her short-term memory loss is permanent. A large white board became her short-term memory, at home, post hospitalization, along with very extensive use of Day-Timers. With her handicap, she has yet to find a system that works well for her and is easy for her to use.

II. INTERACTIONS WITH RISK MANAGEMENT

In late 1991, when I stopped feeling like a deer caught in the headlights, and had some things under minimum control with Diane and our three teenage children, and with my executive search work, I started asking pointed questions. At first we received nice and polite responses.

Things changed when I persisted with more questions, and defenses went up. We were turned over to a senior risk manager for the organization. It became very awkward. There were well-intentioned efforts to explain things, but the attitude was one of superiority. In simplistic terms it felt like: “We know best. Sorry your wife has brain damage. That happens.” I asked for and received a copy of the medical record. I asked for related committee reports. That was denied.

The attitude of that risk manager, in a number of conversations, was a mixture of gruffness, arrogance, condescension, insensitivity, antagonism, confrontation, lack of
empathy, dismissive, and occasional obfuscation. I initiated every conversation and meeting. It was a constant feeling of being pushed into a black hole, of wishing we would go away. This risk manager told me that his role was to save the hospital money, that his was not a philanthropic organization.

III. DIANE IN 1991 AND TODAY

In 1991 Diane was a homemaker, a vibrant woman, and a mother of three children, Sarah 11, Jonathan 14, and Chris 17. She was active in our church – committees, choir and educational involvement. She was attending McCormick Theological Seminary in Chicago as a part time student -- studying theology. She already had one master's degree -- in education -- and was pursuing this second master’s degree, when the respiratory event happened.

Diane’s life was full. She was bright, alert, loving, and competent; a responsible parent and loving wife, and friend of many. She loved to learn. She was a strong person, with an independent personality. She was a flight attendant for Pan Am early in her adult life and loved to travel.

The quality of Diane’s life was forever turned upside down, and inside out, on May 1st and 2nd of 1991. She became dysfunctional. She found it hard to sustain relationships, especially with those working to help her – because she could no longer understand or communicate accurately. Her personality changed significantly. She knows what has happened to her. She doesn’t understand her impact on others. She became very
suspicious, frequently quite negative, sarcastic, argumentative and critical. Her network of friends decreased dramatically.

Diane developed the emotions of a teenager, at best. Her ability to analyze and to reason is gone. Her ability to learn is gone. She cannot read a book – yes, she can read a page, but then turns the page and forgets what she has just read. She cannot prepare a hot meal. She cannot attend a movie and remember the plot, or the cast, or her seat if she goes to the bathroom.

Today Diane lives in an independent living facility, not far from Chris, our oldest son and his wife. She is being advised to move into an assisted living facility, so her medications can be more closely monitored. Chris was named her legal Conservator two years ago.

Our marriage dissolved in the mid 90’s. I literally ran out of give after three years of taking care of her needs, having watched her personality change enormously, and have a significant impact on those around her. For a year, I talked with her about my feelings – not easy when she could not remember conversations from the day before.

My Christian vows are important, and I never thought this would happen. I simply could not be the Old Testament Job. I care a great deal about her, and much of what I am doing relates to that. I am a flawed human being with many weaknesses.
IV. MEDICAL MALPRACTICE LAWSUIT

In a final meeting with the risk management representative, we were offered a financial settlement that was the estimated cost of legal defense of a medical malpractice lawsuit. We turned the offer down. It was an insult. The settlement offer was doubled a couple of months after initiating the lawsuit. That was declined as well. This woman's love of learning and her ability to learn was destroyed. She has no ability to make a living. Her self-esteem was shattered. She needs to rely on others for support. Our health care system failed her miserably.

In 1993, after 21 months of attempting constructive dialogue with the hospital risk management, administration and the physicians involved, we pursued a medical malpractice lawsuit in our United States legal system.

For nine years, the malpractice lawsuit made its way through the system, taking twists and turns. We settled in the fall of 2002 for a very nominal financial amount. Diane basically quit the lawsuit. She could no longer emotionally handle the continued re-visiting of what had happened – to her brain, to her life, to her family, to her marriage, and to her future – and, to re-visit it with people she had likely grown to despise, because she had been treated so shabbily. How was Diane supposed to understand the intrusion of attorneys in her life, when all she wanted was a functioning brain?

The defense attorneys played it textbook and classic – i.e., if you have a brain-damaged patient, and can cause the case to go on long enough, you may eventually wear us
down, and we go away. They were right. They won. It was legal. It was not right, nor fair, nor did it fit the spirit of medicine. This vignette had happened on their watch, on their turf, under their responsibility.

V. OUR THREE CHILDREN

One of my prayers in 1991 was that none of our three children awaken in ten years with serious psychological problems. It has been a challenge and each is doing okay. No one has been comfortable with the divorce, though they seem to understand. We are close. They support my efforts to cause positive change and are giving ideas. They love their mother. They work hard to communicate and to be with her.

These three children, now adults, are a real inspiration to me. They are kind and caring. They have observed and experienced some significant and devastating human life changes. They are dealing with it positively and constructively, and with courage.

VI. RECOMMENDATIONS ON THE ROLE OF THE PATIENT IN THEIR OWN SAFETY

Our Ford family story puts a face on unexpected outcomes. As I share the following comments, let me encourage you to think as patients or family members, as well as providers. This is an assortment of ideas, from my own thinking over the last 15 years and that of others.
1) LET’S BE RESPONSIBLE PROVIDERS OF INFORMATION

- We should know our medical history, our active medications and our allergies. Document this list. Update it every time we visit our doctor or hospital. In your conference packet of information, you should have an item called “The Medication Form.” This is for everyone to use. We developed this in Arizona through the efforts of the AzHHA, ArMA and others. It can be located at www.themedform.com, filled in online and printed out, or printed out and filled in. My patient safety colleague, Ming Ming, from the Chinese Cochran Centre suggests the improper use of medicines, over-use of medications and misuse of medicines is a huge threat to patient safety in China. We know medication errors are a large problem in the United States and all over the world.

- Let’s be a partner and participate with providers. In her book, “Partnering With Patients to Reduce Medical Errors,” Patricia Spath suggests: “It is likely that consumers have NOT been invited to be partners in health care safety because no one ever thought to ask.” She suggests that active participation implies the sharing of information and opinions, joint problem solving and joint responsibility.”

- If one has literacy issues, of any kind, these should be brought to the attention of providers. In the United States alone, over 90 million people have literacy challenges.

- When we have a complaint, we should register it. Merrilyn Walton, a member of the Faculty of Medicine at the University of Sydney in Australia, suggests that patients provide a second set of eyes. We should speak up quickly when we have side effects or adverse events and ask for appropriate action.
Let’s be responsible to ourselves as patients. As JCAHO in the United States suggests in its “Speak Up” program, a patient should self-educate about the diagnosis, the medical test we are undergoing and our treatment plan.

2) LET’S ASK QUESTIONS AND SPEAK UP

- Ask questions. E.g., “Doctor, did you wash your hands?” We should not be intimidated by clinicians, who are human too. Let’s ask about our anesthesia, about our IV drips.
- If we feel we are not getting full disclosure on something, especially a mistake, let’s insist on it. We have the right to know exactly what happened to our body. You have heard this before: “Nothing about me without me.” This is at the heart of patient safety.
- Let’s actively research for doctors and hospitals that provide specialized and high quality services for specific needs, asking for assistance from our primary providers. The Internet is an increasingly useful tool to obtain medical and health information.
- Let’s be open, candid and honest. We need to have the courage and the passion to reach out to providers to speak up. Tell someone to stop if something simply doesn’t feel right. Report questionable behavior.
- Let’s invite a patient advocate, navigator or vigilant partner to help, if we have no family member or close friend who can do this, when we visit the doctor or hospital. Let’s help a neighbor or friend who has no such advocate.
• Let’s ask for second opinions when we feel the need, as regards a diagnosis and suggested treatment plan.

• Let’s ask for medication sheets in the hospital. We can help our caregivers crosscheck our medications. We can also receive some tips about safe medication practices.

• Let’s find out who are the primary physicians and nurses in charge of our treatment while in the hospital. This is a fair and practical question.

• Let’s find out if there will be precautions, interventions, safe guards, checklists and time-outs that prevent wrong site surgery, sponges being left in after a surgery, etc.?

• Let’s find out who I can talk with if I have anxieties and concerns about my care.

• Let’s find out how infections occur, about early symptoms and what we can do to avoid infections, treatment if we develop an infection, and plans for preventing other infections.

• Let’s be diligent and partners in monitoring for compliance with safe practices, including the administration of medications, after verifying my patient identification.

• When Dale Ann Micalizzi’s healthy 11-year-old son, Justin, died in 2001 in the United States from what started out as a swollen ankle, one of her lessons learned, too late, was to beg and to be persistent.
3) LET’S BE EXPECTANT AND PRESUMPTUOUS

- The patient and family member should be considered an active member of the health care team.

- Let’s understand that we are all public. We are all consumers, as patients, or family members, at some point.

- The Picker Institute Europe suggests that patients desire a respect for their values, preferences and expressed needs, information and education, access to care, emotional support, involvement of family and friends, continuity and transition, physical comfort and coordination. We should expect these to be honored.

- I believe there should be accountability by providers to patients. This should be the linchpin to the patient and provider relationship. This accountability may help to balance the unequal distribution of power, especially between a physician and an injured patient. In her article in the Nov/Dec 2003 issue of the HASTINGS CENTER REPORT, titled “Avoiding Cheap Grace – Medical Harm, Patient Safety, and the Culture(s) of Forgiveness,” Nancy Berlinger discusses avoiding the abuse of this unequal distribution of power. From personal experience, I can tell you this is very real.

- Let’s expect, or encourage, providers to do the right thing when things go wrong, including taking responsibility for their own actions, even if it is awkward for them. Hurting patients, hurting caregivers and families in shock are not interested in hearing about hospitals protecting the assets of the organization or saving
money. We have a need to be heard. There is a need for closure --- including an honest and candid understanding of what happened.

- Vasyl Kvariuk, Project Coordinator for the All-Ukrainian Council for Patients’ Rights and Security, in Ukraine, suggests: “Civil Society is a great tool to unite patients who are willing to do something about medical harm which they experienced. Common patients need to get more aware about their rights and what they can do in case of medical services that are not of relevant quality.”

- Jolanta Ewa Bilinska, who is a health journalist in Poland, suggests: “Unfortunately the majority of patients are still passive because they are either not aware of their rights or do not believe in justice.” Meaning, they are not sure how to attain justice.

- If the culture does not encourage us or our families to speak up, then let’s change the culture. Again…speak up! We can be too easily intimidated from actively participating in our own care. Let’s encourage and work on our right to question and to challenge. As Patricia Spath suggests: “When patients have a better understanding of their condition and their treatment, they can become the first line of defense against misadventures and unsafe situations.” Likewise, Merrilyn Walton from Australia suggests that consumer involvement provides another layer of defense against adverse events.

- We should expect that our privacy and confidentiality be honored at all times.

- Let’s expect evidence-based medicine unless there are logical and convincing reasons for other approaches.
• If a mistake happens without our knowledge, even without any harm, if we are part of a mix-up, such as blood drawn from the wrong patient, we should expect to be told about these events. This is the ethical thing to do.

• Let’s expect that candor, honesty, open disclosure and transparency be considered the norm.

• Let’s expect that patients have the right to have their will and experience respected, as suggested by Silvana Simi of the Multiple Sclerosis Cochrane Group in Pisa, Italy.

• Let’s be outraged by too many continuing medical errors, and let’s work with providers to eliminate them.

4) LET’S BE ENCOURAGING AND SUPPORTIVE

• Let’s encourage providers to become patient centric, rather than physician centric. This puts the patient and family at the center of the healthcare system. This should be grounded in mutually beneficial partnerships among patients, families and health care practitioners --- based on dignity and mutual respect. By truly partnering with patients and families, by involving us in decisions about our own care, by gaining the benefit of our help and insights, providers can better plan and deliver care. We can achieve better outcomes. Hospitals and other healthcare providers can improve the care for all patients and increase staff satisfaction. We are moving this direction in Arizona. As a consumer, I am chairing the Patient and Family-Centered Care Advisory Group of the Arizona
Hospital and Healthcare Association. The above statements are in our draft charter.

- Let’s encourage providers to tell the truth, when unexpected outcomes happen, and to apologize. This culture has to start at the top of every provider organization. I suggest that there be a “fire in our belly” for a culture of telling the truth, no matter what. I attended an ALS fund raising dinner in Tucson, Arizona several weeks ago. Jessie Pottinger works for the largest company in Southern Arizona, has ALS, and was the special guest speaker. She is remarkable and has great courage, even with her increasing handicaps. She had much wisdom for those of us in attendance, including this statement: “Life always takes us out of our comfort zone.” Sometimes telling the truth and being candid will take us out of our comfort zone.

- Let’s tell providers: “We believe in you. We care about you. We want to work with you. We are not telling you how to practice clinical medicine, but to listen to the whole person. Be open and candid and honest.” I feel the front line nurse can still be the patient’s best advocate. Patient loads, stress and human frailties get in the way, but let’s remember and enhance the nurse advocacy and partnering role. As Lucian Leape from Harvard suggests: “Let’s help the clinician do the right thing, rather than chastising them for not.”

- Let’s encourage providers to understand the “DEER In the Headlights Syndrome” when unexpected outcomes happen. Patients and families are suffering terribly following these events. We are in shock. We are trying to go on with life while dealing with serious personal and family impacts, one hour, one day at a time.
• Let’s also understand the “deer in the headlights syndrome” that providers go through, when experiencing unexpected outcomes. Physicians and nurses and others did not wake up this morning with the intent or anticipation of hurting someone today.

• Let’s encourage providers to never forget THE HUMAN SIDE. Let’s role model that as patients and family members. Our Ford family medical error experience is only one among thousands and thousands of such death and injury situations that still happen too frequently. Each one requires compassion and personal empathy. There are significant genuine efforts being made to deal with the clinical piece. But….we find the human part to be awkward. We have too much arrogance in health care. We are human beings, with human needs --- patients and staff. We need to remember the dignity of human beings. Cold and unfeeling attitudes will only build barriers. Genuine listening will help break them down. This is about mutual respect. It’s about communications. It’s about teamwork. Let us help to rebuild the trust that has been lost with some providers.

• Let’s empathize with providers that involving patients and families is not easy, that this is a journey in a new direction. Let’s understand that engagement is key, as well as a new learning experience.

5) LET’S PARTICIPATE WITH PROVIDERS AND BECOME INVOLVED

• As patients and family members, let’s volunteer to participate on provider patient safety, quality and patient centered care boards and committees, as well as self help groups. The Dana Farber Cancer Institute in Boston involves patients and
family members on virtually every committee and board in the hospital. Our voices, as patients and consumers, can be heard in many venues. When I am invited to play a role in helping to cause constructive change with provider organizations, I remind these professionals that I am not a clinician. The typical response is: “We have enough clinical experts around the table. We want to hear your voice and ideas, as a consumer.” That is refreshing. There are many people out there like me, who would love to serve on these committees and councils --- to be positive and constructive committee members, and are eager to learn.

- Patients and family members around the world are spawning, or becoming involved, in consumer and patient advocate organizations. We want to work cooperatively with providers regarding patient safety and the aftermath of medical errors as well as with patient and family centered care. Last week I was one of 43 participants in the Patients for Patient Safety conference in San Francisco, sponsored by the World Health Organization World Alliance for Patient Safety. It was a profound experience. This was the first regional workshop of this alliance, in the Pan American Health Organization region -- PAHO -- following the inaugural workshop in London in December. A “London Declaration” on patients for patient safety was developed by the 24 participants from around the world.

- Storytelling by patients and families, through presentations, personal contact and in writing, is important for change and for leadership. Injured patients and those who have lost loved ones to medical errors can share their stories. Providers
need to hear, and are inviting these stories, as a catalyst for causing change. This can help the healing process of those who have lost loved ones or are injured. I encourage an openness and receptivity on the part of providers.

- Some organizations are now inviting patients and family members to take part in multi-disciplinary rounds and asking for their comments. Herman Memorial Hospital in Houston, Texas is one example.

6) LET’S ENCOURAGE AN OPENNESS TO OTHER NEW IDEAS

- Let’s make sure that patients and families have access to the entire medical record, in a spirit of information availability and transparency. Let’s also incorporate and invite input from patients and families into the medical record, as we move into the era of electronic medical records. Not to change what is written by providers, but as supplemental information. We should be able to provide our own notes in the record.

- The desire to create partnerships for the healing process is absolutely essential. The patient and those closest alongside, need an advocacy framework that allows for normative expectations to be understood for all involved, including the on-going caregivers. This testimony came from a family member. He was confronted with a physician attitude of “I am the expert, you must be the controlling husband,” whenever he would ask questions, or seek an understanding as to the diagnosis and short and long treatment plans for his wife. He refused to accept that and was able to effectively dilute the attitude through the involvement of other providers.
• Let’s increase the research on patient and family involvement. Among other researchers across the country, Dr. Saul Weingart and his colleagues at Dana Farber Cancer Institute and Harvard University are conducting substantive studies on patient and family involvement.

• Let’s establish patient advocate training programs. Sarah Lawrence College in New York now offers a master’s degree in patient advocacy. Others are being implemented or are on the drawing boards.

• Debriefing team participants when unexpected outcomes happen. Let’s encourage providers to involve the patient and family in the Root Cause Analysis, and other clinical investigation debriefings. Let’s do away with the classic CYA attitude, and culture, if that exists. I didn’t know what an RCA was when I first started thinking about this. All I knew was that my wife’s brain was seriously damaged. It should not have been, and it was a major surprise. It is offensive to be left out of the very discussions about what happened. Some hospitals are now doing this. I understand the reticence, the legal considerations, tradition, change, role behaviors, ego’s and other human behaviors. I believe it is the right thing to do, will enhance learning all around, and will decrease, rather than, increase the malpractice risk.

• And finally, instead of a divisive spirit when unexpected outcomes happen, let’s be PEACEMAKERS. There are two Bible verses from James that are important to me. I realize and respect that the Bible is not the source of everyone’s faith. I believe, however, that you may understand the Universal spirit of what I am saying. Verses 17 and 18 of James 3 read as follows: “But the wisdom that
comes from heaven is first of all pure; then peace-loving, considerate, submissive, full of mercy and good fruit, impartial and sincere. Peacemakers who sow in peace raise a harvest of righteousness.” I encourage and challenge you all to be PEACEMAKERS. We are each human beings who need each other.

VII. CONCLUDING REMARKS

I love this industry. I care about each of you. I know your responsibilities can seem over-whelming at times. You have many issues to deal with. I appreciate what you do, and have much compassion for each of you.

In my consulting work, I recruit health care senior and mid-level executives, mostly for hospitals and related provider organizations. In my personal interviews, I am very curious about how every candidate views the patient experience. Does he or she have a passion for making the patient experience a good one, for doing what is right and for nurturing a safe environment? I believe everyone in the hospital setting should share this responsibility.....through attitude, behavior and performance. Role modeling should start at the top, with the board and senior management and physician leadership. The absence of strong role models at the top, however, should not preclude staff from modeling up, and with colleagues.

As I prepared for this talk, I invited ideas from a number of people, from around the world. There were two common themes in the feedback --- the focus on the patient,
and teamwork: 1) From Ryan Sidorchuk in Winnipeg, Canada, whose daughter Paige died at too young an age. Her cancer was misdiagnosed, and the wrong treatment given. Ryan suggests: “The one constant in all the interactions a patient will have, in all the different care settings that a patient will encounter, is the patient.” 2) From Kathryn Townsend, a risk manager, patient safety executive, attorney and consultant from Atlanta, Georgia, in the United States. She was a Fellow in the 2001 Salzburg Seminar on “Patient Safety and Medical Error.” Kathryn suggests: “Everyone involved in the patient’s care, including the patient, needs to be willing to take responsibility for the care. The patient can no longer simply hand over her/his care to the physician, nurse, or other providers, and providers can no longer treat the patient as some sort of uninformed interloper. It’s all about building respect and trust in each team member, through communications and teamwork development.”

I have given several patient safety presentations with Monica Berry, the Director of Patient Safety and Risk Management at Loyola University Medical Center in the Chicago area. She developed the metaphor of a fire, which captures the emotions of serious medical error events. She talks about the intense heat that develops, which is the core of the fire. Staff are horrified, just want to get away, and cannot. Patients and families are in shock, wishing it would just go away, and it won’t. None of these people are adequately prepared to manage it. The edges of the fire keep on burning, and sparks ignite unexpectedly.
While the event is a one time exposure for the organization, the impact of the event can last a lifetime for the patient and/or family. This is why I am standing in front of you today. Let me suggest that, instead of the fire continuing to burn, let’s try to manage the fire. Let’s involve patients and families in our work -- to convert anger to passion, to become true partners in our medical care, so as to improve healthcare around the world.

Let me leave you with this encouragement, as well as to set the tone, to live and breathe making the patient experience extraordinarily compassionate and safe and accessible…for every patient. The way we treat each other as human beings is at the heart of how we perform as professionals. We can move away from cultures of shame and blame, to one of compassion and learning. Let’s do it together!

Thank you for listening. I wish each of you many blessings.

Dan Ford
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World Health Professions Alliance
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“Patient Safety: The Patient’s Role.”
Geneva, Switzerland

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