Chapter 5
A Home of Our Own: The National Patient Safety Foundation

Prior to the first Annenberg Conference, none of us who were interested in patient safety had given any thought to forming a national organization—except for Marty Hatlie, the AMA's legal counsel. Marty was intrigued by the success of the Anesthesia Patient Safety Foundation (APSF) that Jeep Pierce and Jeff Cooper had founded. He envisioned the formation of a similar national organization as the centerpiece of the refashioning of the AMA's stance on patient safety after its stinging legislative defeat of tort reform.

Hatlie began to internally advocate that the AMA establish a similar organization for all of healthcare, and he ultimately persuaded the executive vice president, Jim Todd, and incoming chair of the Board of Trustees, Nancy Dickey, that they should do this. At Annenberg, Dickey, together with two other AMA trustees, Don Palmisano and Tim Flaherty, decided on the spot to announce that the AMA was founding an independent National Patient Safety Foundation (NPSF).

Some questioned whether the AMA would really permit the Foundation to be independent. Dennis O'Leary, head of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), was particularly "leery," as was I, having been snookered by the AMA in a previous research program. But we all decided to give it a try, and JCAHO signed on as a sponsor. I thought having a national organization would make a huge difference in improving the visibility of patient safety, which in fact it did.

A few months after Annenberg, in February 1997, the AMA convened a Consensus Conference of a broad group of healthcare leaders

L. L. Leape, *Making Healthcare Safe*,
https://doi.org/10.1007/978-3-030-71123-8_5

and safety experts to help it develop the NPSF agenda. Along with several others, I gave a talk to share my vision of what we needed to do for patient safety. Marty Hatlie laid out the objectives of NPSF, his hopes for collaboration across multiple stakeholders, and the details of how it was to be organized.

The group concluded that the first task for NPSF was to establish priorities. The first priority should be to support patient safety research. NPSF could also help by improving taxonomy and making data available on safety to a wide audience. Most importantly, we agreed that, unlike typical medical professional organizations, all stakeholders should be represented.

Unbeknown to most of us at the time, when Dickey and friends announced the formation of the NPSF at Annenberg, it was far from a done deal. It had not been approved by the Board of Trustees of the AMA. It turned out that many Board members were not at all sure that the AMA should be involved in anything to do with medical errors, much less sharing control with other organizations.

It took 7 months and six Board meetings before Dickey and her colleagues convinced them it was the right thing to do. However, once it did so, the AMA was generous in its support, providing $1,000,000 over 3 years, including valuable in-kind support in terms of office space and staff for the foundation in its early years.

Dickey and Hatlie were also very successful in raising money from outside groups. By the time of its official founding in May 1997, funding had been secured from multiple commercial sources, including major grants from 3M ($1m over 3 years), CNA HealthPro ($1m over 3 years), and Schering-Plough (500K over 3 years) as well as substantial contributions from the Physician Insurers Association of America, DuPont, Merck, Hoffman-La Roche, MMI, Kaiser Permanente, and Hoechst Marion Roussel.

The first meeting of the NPSF Board of Directors took place July 28–29, 1997, in Chicago. There were 40 directors in all, representing a wide range of stakeholders. Twelve of us comprised the Executive Committee: Richard Cook, anesthesiologist and safety researcher at the University of Chicago; Nancy Dickey, AMA president; Steve Fountain (Physicians Insurance Association of America); Linda Golodner (National Consumers League); Doni Haas, safety leader at Martin Memorial Hospital; Carol Ley (3M); Jim Macdonald (CNA); Henri Manasse (American Society of Healthcare Pharmacists (ASHP)); Jeep Pierce (Anesthesia Patient Safety Foundation); Diane Pinakiewicz

(Schering-Plough); John Rother (AARP); and myself. Hatlie served as executive director and did all the work of organizing and planning.

The Executive Committee developed a simple mission statement: to assure patient safety in the delivery of healthcare. We would do that by promoting research on error, promoting solutions to prevent patient harm, developing information and educational approaches that advance patient safety, and raising awareness. From the beginning, NPSF funded research through a Research Committee chaired by Jeff Cooper, who held a similar role with the APSA. By the time of the AMA's official announcement of the establishment of the NPSF in October, it was fully functioning.

The first major event the NPSF sponsored was a public briefing in New York on October 9, 1997. Charles Meyers of ASHP issued a public call for bar coding of drugs. But the news hook was the report of a public attitude survey done by Harris Associates of 1513 interviews in August 1997, commissioned by Research!America, and presented by Mary Woolley, its president.

The survey results confirmed the extent of stereotypes about patient safety and highlighted the lack of public awareness of it as a problem, even though safety issues were pervasive. The study found that 42% of respondents had been affected by a medical mistake personally or through a friend or relative, and 84% had heard of a medical mistake situation.

Half of the respondents thought carelessness, improper training, and poor communication were the major causes of mistakes; 75% thought that better training and preventing physicians with bad track records from providing care would be the most effective solution to medical mistakes. A minority believed that lawsuits or government regulation was effective. Healthcare was perceived as moderately safe (5 on a 7-point scale)—and safer than nuclear power (which was far from true), but less safe than airline travel. It was clear we had a long way to go.

The first meeting of the NPSF was held in Chicago December 15–17, 1997, and featured a Workshop on Assembling the Scientific Basis for Patient Safety Research, led by Richard Cook and David Woods, that drew international experts. They made the case for a systems approach and the need to seriously investigate errors. They labeled their session a "Tale of Two Stories," contrasting the usual response to celebrated cases—mostly blame and punishment—with in-depth investigation of a serious adverse event that leads to systems changes.

Meanwhile, at the AMA, all hell was breaking loose. Jim Todd, the CEO who strongly supported founding NPSF had retired and had

David Woods and Richard Cook. (All rights reserved)

been replaced by John Seward. One of his first acts was unprecedented and an absolute disaster: he quietly contracted with Sunbeam Products in the summer of 1997 for the AMA to provide, for a fee, an AMA seal of approval of Sunbeam appliances [1].

The AMA membership (and the public) revolted, and there were calls for senior executives, Board chairman Nancy Dickey, and the entire Board of Directors to resign. NPSF funders were outraged and began to grumble about NPSF needing to distance itself from the AMA. AMA management scrambled, fired the CEO, and ultimately paid Sunbeam $9.9 million to break the contract [2]. Things gradually quieted down.

Despite all this, the NPSF rolled ahead. Patient safety was beginning to be talked about widely. In the report of the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, led by Don Berwick, head of the Institute for Healthcare Improvement (IHI), reduction of error was one of six recommended national aims, and NPSF was cited. JCAHO revised their sentinel event policy to make reporting voluntary, and the Agency for Healthcare Policy and Research (AHCPR) (later renamed the Agency for Healthcare Research and Quality (AHRQ) identified patient safety as a priority. In November 1998, we held the second Annenberg Conference.

Also in 1998, Ken Kizer, undersecretary for health in the Veterans Administration, established the VA National Patient Safety Partnership and worked with NPSF to explore issues in changing institutional culture. At the urging of George Lundberg, editor of JAMA, Kizer joined

me, Steve Schroeder from the Robert Wood Johnson Foundation, Lundberg, and others in issuing a call for action to improve patient safety by a clear focus on medical error [3].

But most importantly, Ken Shine, president of the Institute of Medicine, decided to put quality of care and patient safety on its agenda. Advised by staff who had attended the Annenberg Conference, he convened the IOM Quality of Care Committee. A year later the Committee would issue the legendary IOM report, *To Err Is Human*, that rocked the world (Chap. 9).

Over the next 20 years, the NPSF initiated an impressive array of programs to improve patient safety. In the early years, the focus was on raising awareness and engaging all stakeholders. We viewed NPSF as a catalyst, a force for change, designed to facilitate dialogue and cooperative work on patient safety among diverse stakeholder groups.

To operationalize these goals, NPSF quickly developed activities and initiatives to advance the field. These early years were incredibly productive. From the beginning, NPSF engaged consumer groups and included patients on its Board. The well-funded research grant program facilitated the growth of a cadre of young investigators who focused on this brand new field of patient safety research. The NPSF annual meeting, later named the Patient Safety Congress, provided a forum for presentation of research, education in patient safety, examples of successful practices, and, of course, networking. It attracted an increasing number of attendants each year as the movement took hold.

NPSF also sought to facilitate the *application* of research. To this end, early on it created a comprehensive literature *Clearinghouse*, providing access to literature covering all aspects of medical error and patient safety, as well as a monthly survey of literature, called *Current Awareness* that continues today.

By 2001, the Clearinghouse offered more than 2500 articles, papers, and books on patient safety and healthcare error. A *NPSF website* was created to provide resources, reports, newsletters, and information to practitioners and the public on how to get involved in patient safety initiatives.

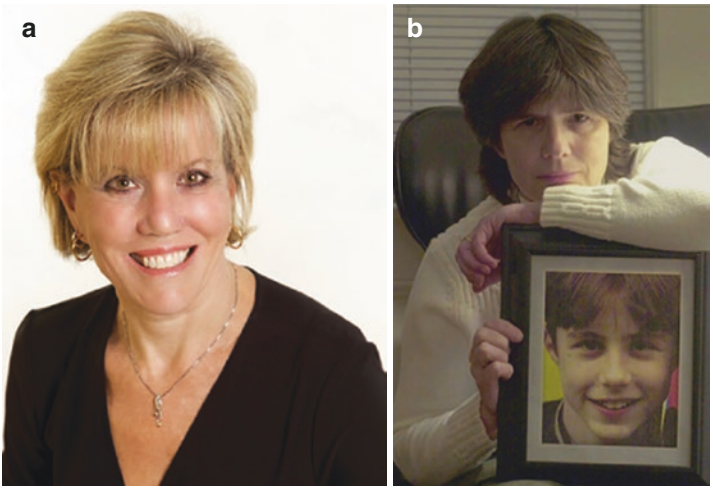
For direct help to patient safety practitioners, NPSF established a *Patient Safety ListServ* and a quarterly newsletter. Within a year, the ListServ e-mail discussion group included more than 1300 active subscribers and participants who exchanged patient safety information, strategies, suggestions, and resources.

A newsletter, *Focus on Patient Safety*, gave patient safety professionals up-to-date information on patient safety research and new practices and ideas and monitored the expansion of patient safety initiatives worldwide. All these resources were designed to help those "in the trenches" doing research or redesigning their practices to improve safety.

To advance the role of patients in safety, in 2001 NPSF established a *Patient and Family Advisory Council* (PFAC) to provide input to all Foundation initiatives. The PFAC included the leaders of the major patient advocacy groups. From the beginning of the movement, mothers of children who had died or were seriously harmed by a medical error had spoken out, most notably Sue Sheridan, Helen Haskell, Ilene Corina, and Sorrel King. They were welcomed by the leaders of the movement and contributed to the program at every Congress.

To facilitate training of the next generation of patient safety leaders, NPSF collaborated with the American Hospital Association's Health Research and Educational Trust to establish a *Patient Safety Leadership Fellowship Program*. NPSF also reached out to its corporate and institutional members, creating a *Corporate Council* to educate and involve industry representatives.

In 2002 NPSF initiated *Stand Up for Patient Safety*, a program for hospitals and healthcare systems committed to serious effort to



(a) Sue Sheridan, **(b)** Helen Haskell and Lewis. (All rights reserved)

(c) Ilene Corina, **(d)** Sorrel King and Josie. (All rights reserved)

improve safety. The program offered practical tools to enhance existing patient safety and quality improvement initiatives, educational programs, information resources, leadership seminars, and online forums for sharing patient safety innovations and best practices. The program expanded substantially in 2004 with funding from AIG, the large insurance company, which brought its hospitals into membership.

At the prompting of patient advocate, Ilene Corina, NPSF initiated the first annual *Patient Safety Awareness Week*. It is celebrated in March, coinciding with the date of the death of her son, Michael, from a medical error. The PFAC published a National Agenda for Action: *Parents and Families in Patient Safety – Nothing About Me Without Me*, a white paper outlining how NPSF would lead in education, culture, research, and support of patient engagement. The NPSF website was generating more than 15,000 hits each week. In 2005, the patient safety research community's dreams were realized with the launch of the *Journal of Patient Safety*, with Nancy Dickey as editor in chief.

Despite these awesome early accomplishments of NPSF, there was turmoil within the organization. Its internal culture was suffering. Almost from the beginning, turnover of management and chronic staff unhappiness were the norm. The Board, dominated by the AMA, took the classic position that it should not interfere with the CEO or

interact with any staff, so these problems remained unresolved. But from the beginning, many other Board members were concerned about NPSF's lack of independence from the AMA.

The AMA's generosity had made the Foundation possible, but the nature of the affiliation with the AMA, including its provision of staffing and office space, represented control. In 2004, the issue came to a head. The Board voted to separate NPSF from the AMA and elected founder and Board member Diane Pinakiewicz to be the president. The AMA was not pleased. It canceled all its funding, including, sadly, the fund for research named for Jim Todd, which had supposedly been endowed in perpetuity.

Pinakiewicz turned things around. She created a new business strategy and moved the headquarters first to distant and inexpensive space at the Massachusetts Museum of Contemporary Art (MASS MoCA) in North Adams, MA, and then to Washington, DC. NPSF began to develop business partnerships across the industry, moving from a contributory revenue model to an earned revenue model. Programs such as Stand Up for Patient Safety and Corporate Council were redefined and grown significantly. The annual Congress grew in number of attendees as well as in the number of commercial exhibitors.

In 2007, in response to a proposal from its chairman, Paul Gluck, and president Pinakiewicz, the NPSF Board decided to establish a think tank to be called the *Lucian Leape Institute*. Over the years,

Diane Pinakiewicz. (All rights reserved)

NPSF had created a group of distinguished advisors, leaders in patient safety who were not on the Board but whose support was important to NPSF's mission.

Paul and Diane decided to harness their expertise to provide strategic guidance at the systems level and to identify and tackle the issues that were beyond the capabilities of individual organizations. The Institute was to be the vehicle for doing that. They asked me to chair it. The Board promised adequate financial support for its work.

I liked the idea of an institute for strategic planning but was, to say the least, nonplussed by having it named for me. I wryly observed to them that an "institute" is usually named for someone after they die or contribute a sizeable sum to endow it! I had done neither. But the opportunity to brainstorm with some of my favorite and smartest people was appealing. Further information about the efforts of the Lucian Leape Institute will be found in Chap. 22.

Under Pinakiewicz's leadership, NPSF extended its programs considerably. An important step forward was the formation of the *American Society of Professionals in Patient Safety* (ASPPS) in 2011 to provide caregivers who devoted their efforts to patient safety higher visibility and standing. Membership was open to individuals who were working in formal patient safety roles, as well as clinicians and executives, all in the healthcare workforce, patients, and those working in industry who had a commitment to patient safety.

But more was needed if patient safety was to be recognized as a true discipline. Accordingly, in 2011, NPSF established the *Certification Board for Professionals in Patient Safety*. The Board set appropriate educational and training requirements and developed a qualifying examination for its credential, Certified Professional in Patient Safety (CPPS). In recognition that patient safety must be a team effort with broad responsibility, certification is open to interested parties across multiple disciplines. Within 4 years 1100 individuals were certified. To meet the educational needs of students and professionals, NPSF created a comprehensive online *Patient Safety Curriculum*. By 2018, over 5000 had taken this online course, and 3000 individuals held the CPPS credential.

In 2011, NPSF severed its sponsorship of the *Journal of Patient Safety* which had appointed Charles Denham as editor without consulting NPSF. Denham had already fallen out of favor with NPSF

because he had produced a video for the annual Congress and then refused to let NPSF have further use of it, claiming copyright protections. Denham later was forced to leave the National Quality Forum because of undisclosed conflicts of interest and forced to resign as JPS editor (see Chap. 11).

In 2013, Tejal Gandhi, patient safety researcher and head of safety for Partners Healthcare, became president and CEO of NPSF. At the Board's behest, she implemented a new strategic plan to incorporate workforce safety as a critical aspect of patient safety. This was an outgrowth of the LLI white paper on finding joy and meaning in work, *Through the Eyes of the Workforce* [4]. The NPSF vision statement was expanded: "to create a world where patients *and those who care for them* are free from harm".

LLI increased its thought leadership. By 2015, it had published its fifth white paper on transforming concepts. It then convened experts to evaluate best practices for root cause analysis, a core function of safety and risk professionals. The report, *RCA²: Improving Root Cause Analyses and Actions to Prevent Harm* [5], was very well received by the field, and over 7000 persons participated in the initial webcast in 2015 to discuss the report. Since that time, many hospitals

Tejal Gandhi. (All rights reserved)

and health systems in the USA and abroad have adopted the *RCA²* methodology, and the RCA2 report continues to remain one of the most downloaded reports.

Another high impact report released in 2015 was *Free from Harm: Accelerating Patient Safety Improvement Fifteen Years after To Err Is Human* [6]. The report was the product of a roundtable convened to reflect on what had been accomplished in patient safety since *To Err Is Human* and where the field needed to go. *Free from Harm* has been widely cited, and its eight recommendations have become the basis for safety strategies for a range of health systems as well as for several national safety agencies globally.

Recognizing that leadership is the key to creating a culture of safety, in 2017 LLI partnered with the American College of Healthcare Executives to convene a series of roundtables that examined how leaders can create and sustain a culture of safety. The resulting report, *Leading a Culture of Safety: A Blueprint for Success*, identified practical strategies and tactics to truly advance a safety culture and has had widespread dissemination globally [7]. Many hospitals, health systems, state hospital associations, and countries are using the Blueprint to advance their culture efforts.

But all was not well with the NPSF. While its work continued to expand, it was unable to get adequate, stable, assured funding. At the beginning, a number of generous funders joined with the AMA to get it started. Their support continued for the first few years, but none were willing to commit to long-term annual support. NPSF had come to rely on grants for specific projects and on income from programs such as *Stand Up for Patient Safety*, the *Certification Board for Professionals in Patient Safety*, and the *Patient Safety Curriculum* and fees from commercial exhibitors at the annual Congress. It was not enough.

The problem was resolved in 2017, when NPSF merged with the Institute for Healthcare Improvement. In addition to providing the needed financial support, IHI's global network and forums greatly extended NPSF's reach and provided the means to move thought leadership to action through its collaborative models, expanding safety programs to health systems around the globe. The strategic planning Lucian Leape Institute continued as an active program at IHI.

The impact of NPSF over the years was enormous. From the beginning it was the driving force behind the patient safety movement. Without it, it is unlikely there would have been a national effort; at best, it would have been a slow and stuttering one. AHRQ played a crucial early role in funding patient safety research and advancing training and various programs, but it was NPSF that provided the forum for bringing together the various stakeholders, increasing their awareness, and getting their buy-in. NPSF educated America, and to some extent the world, on what patient safety was all about, and it created the infrastructure that would change a powerful idea into a movement.

Through its support of research, facilitation of communication and education, and dissemination of new safety information, a community that put patient safety "on the map" for many was built. It provided invaluable information, assistance, and identity for individuals who were just beginning to get interested in this new field. It brought together leaders and experts to deepen our understanding of the myriad complex barriers to making healthcare safe and to develop strategies to overcome them.

Its programs stimulated hospitals, educators, and policy-makers to make a commitment to improving safety and provided them with tools to do so. And NPSF embraced diverse groups outside of organized medicine, such as private corporations and patient advocates, giving them a voice and the means to have an impact.

NPSF provided a home for the burgeoning field of patient safety specialists, first with a specialty association, later with specialty certification. The annual Patient Safety Congress conference became the place for safety professionals to come together to learn and share research and experience. The NPSF provided the structure and support for the new patient safety movement. Without it, the movement would have been slow and halting in coming. NPSF was for many years the soul of patient safety.

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