



## National Patient Safety Authority?

A little over a year ago I connected through Atlanta heading home from what was my last meeting in Washington, DC before COVID shut down travel. As my flight to Salt Lake took off, a faint smell of smoke wafted through the cabin. Just minutes later the pilot announced we were returning to Atlanta. There we were met on the tarmac by fire trucks who first inspected our heavy plane (landing laden with fuel can cause landing gear failure). Then the trucks escorted us through the rain to the gate. The pilot shared that the smell of fire was much stronger in the cockpit. They suspected an electrical issue. Two hours later we were on our way with new equipment and crew.

As I've studied how airlines handle such situations, I found that prior to landing the pilots had to go through numerous safety checklists. They may have dumped excess fuel. They most likely were given a priority landing vector and brought in on the airport's longest runway. As passengers, we were not aware of the tense moments the pilots must have had in the cockpit as they planned to land a heavy airplane in the rain with a potential fire onboard. The Delta pilot's announcements and the flight attendants were calm and reassuring, even while they handled an emergent situation.

In many industries, consumer safety ranks first in both employee and consumer education. McDonald's famously teaches "QVSC, quality, value, safety and cleanliness." At Disney, the safety of guests on rides is drilled into the cast members. Any break down in safety protocols can result in reassignment or dismissal for the cast member responsible. In aviation, each team member has specific safety protocols to follow every flight and each member trains for additional duties based on various scenarios that could occur.

Could you say the same about healthcare?

In the world of aviation an unthinkable safety problem happened a few years ago. A newer airplane, the Boeing 737 Max, seemingly for no reason began to drop out of the sky. Two precipitous descents were unrecoverable, resulting in both planes crashing and significant loss of passenger and crew lives.

In analyzing what caused the problem the National Transportation Safety Board (NTSB) traced a software issue back to the manufacturer and a rush to production. Normal safety processes in development and subsequent pilot concerns had been dismissed in the name of faster delivery. In the short run delivery timelines were met. In the long run, circumventing safety protocols meant the entire line of aircraft was grounded while solutions to the software problem causing engine surge were found and planes were reprogrammed.

Do we even know in healthcare why the same safety issues may occur repeatedly? Why don't we have a federal healthcare agency focused on investigating harm events or cataloging reports of errors? Where is the accountability for keeping healthcare safe?

For at least 20 years, patient safety advocates have been calling for [oversight in healthcare modeled after the aviation field](#). In 2019 [the World Health Organization called upon every nation to develop national solutions](#). Several organizations are now mounting new advocacy efforts in the United States, [asking for the creation of a federal agency](#). The Jewish Healthcare Foundation has formed a coalition to establish a National Patient Safety Authority modeled closely after the NTSB, with power to investigate events and do predictive assessments of risk. The Patient Safety Movement Foundation is calling for patient safety "moonshot" that would put in place a [Federal Health Care](#)

[Administration](#) that would go farther, with power to set and enforce national standards in healthcare, modeled after the broad powers of the Federal Aviation Administration. Consumers Advancing Patient Safety supports these efforts, and others like them. Let's all work together to track and prevent harm in healthcare. **-Lisa Morrise**

*Consumers Advancing Patient Safety is a 501c3 not-for-profit organization that envisions a partnership between consumers and providers to create global healthcare systems that are safe, compassionate and just. CAPS champions patient safety led by consumers in partnership and collaboration with providers.* To support CAPS's work, please consider donating through your VENMO account to @CAPS-PatientSafety. If you prefer to use PayPal, our account is under Consumers Advancing Patient Safety or go to [www.paypal.me/patientsafety](http://www.paypal.me/patientsafety).



## CAPS Consumer Advisory Panel Profile

*Helen Haskell was nearing completion of a PhD in African Archaeology from Rice University when her son, Lewis, passed away from medical error. Helen became a powerful patient advocate in her home state of South Carolina and then North America and the world. She and her husband, Bar Blackman, quarantined during the COVID-19 crisis in Georgia, along with their grown daughter, Eliza Blackman. Helen Haskell is the President of the Board of Directors of Consumers Advancing Patient Safety.*

### **CAPS: When did you start your advocacy?**

**Helen Haskell:** I became an advocate after the death of my 15-year-old son Lewis, who died of medical error at a teaching hospital in South Carolina in November, 2000. Lewis was a healthy child who was in the hospital for elective surgery. He died from a perforated ulcer caused by the NSAID pain medication, ketorolac, that he had been given after surgery. He began going downhill early on a Sunday morning, when staffing was low and the staff who were there were inexperienced in pediatrics or post-surgical care. The only surgery team member in the hospital was an intern who had just begun her pediatric rotation. None of the nurses or residents recognized that his situation was an emergency, and Lewis was allowed to linger and die over thirty hours.

We were horrified by the chaos we witnessed in the hospital, and even more horrified when we realized that this disorganization seemed to be business as usual in a teaching hospital. We started advocating in South Carolina for a law in Lewis's name that included a requirement that hospitals have emergency access numbers for families. That legislation passed in 2005. In South Carolina, patients and families can contact their physicians directly when they are in the hospital, and hospitals are required to have a rapid response mechanism for families to escalate care when they feel concerned about their loved one.

I didn't think the Lewis Blackman Hospital Patient Safety bill would pass. But it received a lot of publicity. Lewis had been a top, well-known student. He had been in the news quite a bit and had many friends. It passed about five years after he died.

That started a whole chain of events for healthcare safety and quality in South Carolina. When we were working on the Lewis Blackman Act, we developed a coalition of consumers and healthcare interests. The next year, with the help of Consumers Union, we worked with the same partners on the South Carolina Hospital Infection Disclosure Act (HIDA). The HIDA Act passed the General Assembly unanimously, and I served on the oversight committee for many years. Along with other Consumers Union members I have continued to collaborate with the CDC on hospital-acquired infections up through the present. The Medical University of South Carolina, where Lewis died, created a Lewis Blackman Chair of

Clinical Effectiveness and Patient Safety, endowed by the state of South Carolina. They also set in motion a proposal for a statewide patient safety and quality plan that was funded for many years by the Duke Endowment in North Carolina. As part of that program, the SC Hospital Association took on patient safety as a major part of their mission. I and other patient advocates worked with the SCHA on many patient safety initiatives, including an annual patient safety symposium where we presented patient safety awards in Lewis's name. Jan Vick, Dianne Parker, Lisa McGiffert, Rosemary Gibson and other patient advocates were among the prominent winners of that award.

**CAPS: How has your advocacy evolved over the years?**

**Helen:** Gradually, my advocacy expanded beyond South Carolina to more national work and then international. I had started Mothers Against Medical Error in 2002, and MAME was central to the passage of the Lewis Blackman Act. We initially had a national network operating mainly by email. It's now mainly active on social media, including Facebook. Also in 2002, Rosemary Gibson wrote about a number of families and patients, including Lewis, in her book, [Wall of Silence: The Untold Story of the Medical Mistakes that Kill and Injure Millions of Americans](#). These families were really the core of the national patient movement in those days and I learned an enormous amount from them. Many of them are still active with CAPS. In 2009 I joined the CAPS board of directors and in 2010 I was invited to serve on the AHRQ National Advisory Council. I went from advocating for reform through legislation at the state level to working with a variety of national and international organizations including the National Patient Safety Foundation, the Institute for Healthcare Improvement, and the [World Health Organization](#). One of my favorites is the International Society for Rapid Response Systems, a group of critical care professionals I first met when I crashed their initial rapid response conference in 2005.

**CAPS: What projects have you been involved in?**

**Helen:** It's hard to talk briefly about all the projects and organizations I have worked with in 20 years. I have been on at least 15 projects with the [Association for Healthcare Quality and Research](#), ranging from clostridium difficile environmental scans to diagnostic safety capacity building. I have served on a number of committees at the [National Quality Forum](#), most importantly, since 2011, the Measure Applications Partnership hospital workgroup, [which](#) recommends performance measures to CMS for use in federal health programs. I was part of Partnership for Patients and other initiatives at CMS. I work with the Lown Institute and its Right Care Alliance on overuse and overmedication. I was chair of the patient engagement committee at the [Society to Improve Diagnosis in Medicine](#) (SIDM) for five years and have been a leader in organizing SIDM's patient summits on diagnosis since they began in 2014. In 2014 WHO asked me to co-chair the Patient Safety Advisory Group with Margaret Murphy from Ireland. I helped develop the patient materials for the WHO Global Medication Safety Challenge and co-chaired the patient engagement workgroup for the new [Global Patient Safety Action Plan](#). (The Third Draft released in January 2021 is available at the link.) The Telluride Patient Safety Summer Camp, where I have been faculty since its first meeting in 2005, has a special place in my heart. I owe an incalculable debt to its leaders for developing a widely viewed educational video about my son, [The Lewis Blackman Story](#). Finally, as I mentioned earlier, I've worked for 15 years with Consumers Union, first as part of their Stop Hospital Infections campaign, later as part of the Safe Patient Project, and now as a member of the leadership team of its successor organization, the [Patient Safety Action Network](#).

**CAPS: What would you recommend to persons who want to advocate for quality and safety?**

**Helen:** I think there are two levels. First, I would say: do your homework. It is important to understand the nuances of what you are advocating for, because in healthcare things are often not what they appear to be on the surface.

Reasonable minds may differ, but it's critically important to make informed arguments and take informed stands. Second, I think demeanor is important. Model the behavior you would like to see from clinicians. To me that means humility, courtesy, and openness, but standing your ground on what you believe in.

I am often humbled by the wisdom of patient advocates who work in hospitals, and especially the parents of children with chronic illness. Patient advocacy is mission driven, but it is often hamstrung by underfunding, and people are often not given the scope to do what they can do. There's a huge pool of talent not being utilized.

**CAPS: What would you recommend to health care systems to improve quality and safety?**

**Helen:** We need more transparency. I believe that the biggest problem we face in achieving safer healthcare is the secrecy that is built into the system. Twenty years without significant improvement says to me that confidentiality is not working. The other big issue is the weakness of the patient voice. I think that the CAHPS surveys – Consumer Assessment of Healthcare Providers and Systems – have done a lot to improve patient representation, especially in hospitals. But we need a lot more. We need the patient voice strengthened everywhere. We still do not have any systematic way of knowing what actually happens to patients or what they think about their healthcare.

We need a better use of technology and better implementation of known best practices. We have software programs that can detect an error or a deteriorating patient in real time and reduce hospital mortality significantly. The same thing can be accomplished by effective deployment of resource nurses and outpatient care outreach, but health systems have to be willing to make the investment in patient safety.

**CAPS: What are your future plans?**

**Helen:** I am working with the [Patient Safety Movement Foundation](#) to propose a national patient safety agency that is modeled in many ways on the aviation safety system. What is exciting to me is the possibility of using data to detect trends in healthcare delivery, patient harm, and patient response to treatments. I'd like to see it supplemented by regular input from patients and healthcare workers. This is our chance to find out what is going on in real life with patient safety, and what really has value for patients. I'll continue with my other projects, especially with WHO, but I think this is our best chance of finally seeing improvement in patient care.

**CAPS: Thank you, Helen Haskell. Helen may be reached at [Haskell.helen@gmail.com](mailto:Haskell.helen@gmail.com).**

The videos in a series of COVID-19: Patients, Families and Providers in Conversation may be found at this link:

<https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>

*These videos are a collaboration of three organizations: Consumer Advancing Patient Safety (CAPS), Project Patient Care (PPC) and Healthcare and Patient Partnership Institute (H2Pi).*

You can view all of these videos on the Consumers Advancing Patient Safety YouTube Channel. Please go the link and be sure to hit subscribe **and** notify so you will know when a new, relevant video has been uploaded!





Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here:

## Thoughts about the TakeCharge campaign from Patient Advocate Lori Nerbonne

I'm a nurse, turned patient safety advocate. And I want to let you in on one of the best-kept secrets many of us in this field have learned as we help patients navigate our complex healthcare system.

But before I do that, I want to introduce you to a lady who has pioneered this secret by packaging it into an easy, user-friendly way that all of us as eventual patients or their advocates can begin using right now. Whether you are a college student living thousands of miles away from your parents, or the daughter or son of an aging parent, or somewhere in between: Listen up! This is for you.

Ilene Corina is a feisty ball of energy with a Long Island accent. To meet her is to instantly feel like you want to get to know her. She runs a non-profit organization in New York called [The Pulse Center for Patient Safety Education and Advocacy](#). She has been moving the bar in patient safety and advocacy since the late 1990s when she began looking for a surgeon for her young son.

Two life-changing healthcare experiences had given Ilene the keen awareness and knowledge that researching and choosing a surgeon carefully was a necessary and basic first step. You see, Ilene had tragically lost a child in 1990 from excessive bleeding after a tonsillectomy. Her repeated reports of concern about her son's condition were dismissed for a week before he died. After the birth of her youngest son, she also spent lots of time as a parent in a hospital Neonatal Intensive Care Unit (NICU).

Ilene began meeting with other patients who had similar experiences and started turning those stories into action. She attended conferences, accepted the opportunity to serve on patient safety boards, lobbied for patient safety laws and became a bedside patient safety advocate. In the end, she realized her passion and the real need was in educating and empowering people before they became a patient, and to give them tools to help them be assertive and involved in their own health care.

This is where I get to tell you about this patient safety secret: Prepare well in advance of a medical appointment or hospital stay and take charge of your medical care. Don't be a bystander. The stakes are simply too high.

Ilene and The Pulse Center's volunteers have taken this further and turned this important preparation into 5 easy steps that any patient, caregiver or family can do well ahead of a healthcare encounter. [The TakeCHARGE Campaign](#) was launched in 2019 and guides individuals or groups (Seniors, Employees, Teachers, College or High School Students, anyone!) through these easy but powerful steps:

1. Understand & Complete Your Advance Directives
2. Keep a Record of Your Medical History & Current Medications
3. Prepare for Doctor Visits/Make a List of Questions
4. Prevent Infections/Ask Caregivers to Wash Their Hands
5. Use an Advocate/Be an Advocate for Others



This March, during National Patient Safety Week (March 14th to 21st), the TakeCHARGE Campaign kicked off, raising awareness for these 5 easy steps on social media platforms and in the news. To share the Campaign's posts, you can go to the [TakeCHARGE website](#) or [Facebook Page](#) where you'll soon find memes, short videos and other ways to raise awareness.

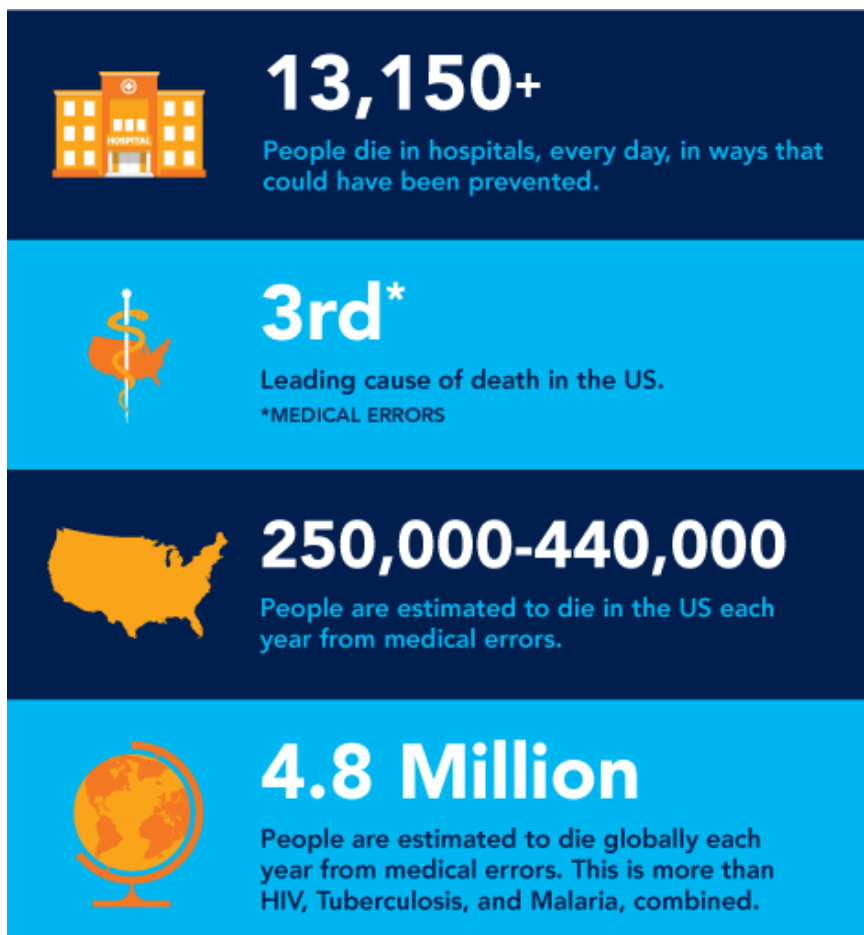
If you'd like to be more involved in the TakeCHARGE program, become a sponsor, have someone speak to your group, or implement the 5 easy steps in your workplace, community or other setting, please reach out to the program [here](#).

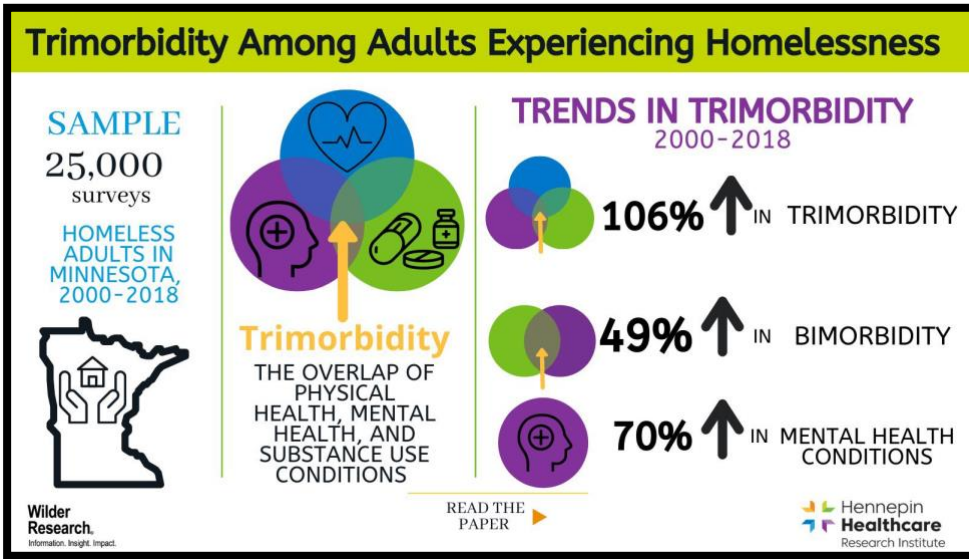
Thank you to Ilene Corina and Pulse of NY for helping all of us prepare ahead for patient safety. To quote Ilene: "We want people to think about this program as a way of life before they become a patient because it should be a part of our health care preparation routine." She gives the example of asking a doctor or nurse to wash their hands: "If only one of us does it, it feels like a barrier. If all of us do it, it's an expectation."

I couldn't agree more. – Lori Nerbonne

## Graphics Garden

### From the Patient Safety Movement Foundation:





From Patient Advocate Janet Tuft's Twitter page.

WebMD

## FACE MASK MISTAKES

✗ It doesn't cover your chin.	✗ It sits below your nose.	✗ It covers only the tip of your nose.
✗ It's too loose.	✗ You keep touching it.	✗ You keep taking it on and off.

### THE RIGHT WAY TO WEAR A FACE MASK

The top edge sits on the bridge of your nose.		It's snug, without gaps between the mask and your face.
The bottom edge sits under your chin.		Wash your hands after you take it off.

SOURCES: World Health Organization, San Francisco Department of Public Health, National Jewish Health.  
REVIEWED BY Hania Bhargava, MD, April 17, 2020.

# ACCEPTANCE & UPTAKE of SAFE & EFFECTIVE VACCINES AGAINST COVID-19

On October 15 2020, the TAG met to provide input to three questions posed by WHO colleagues in the Department of Immunization, Vaccines and Biologicals

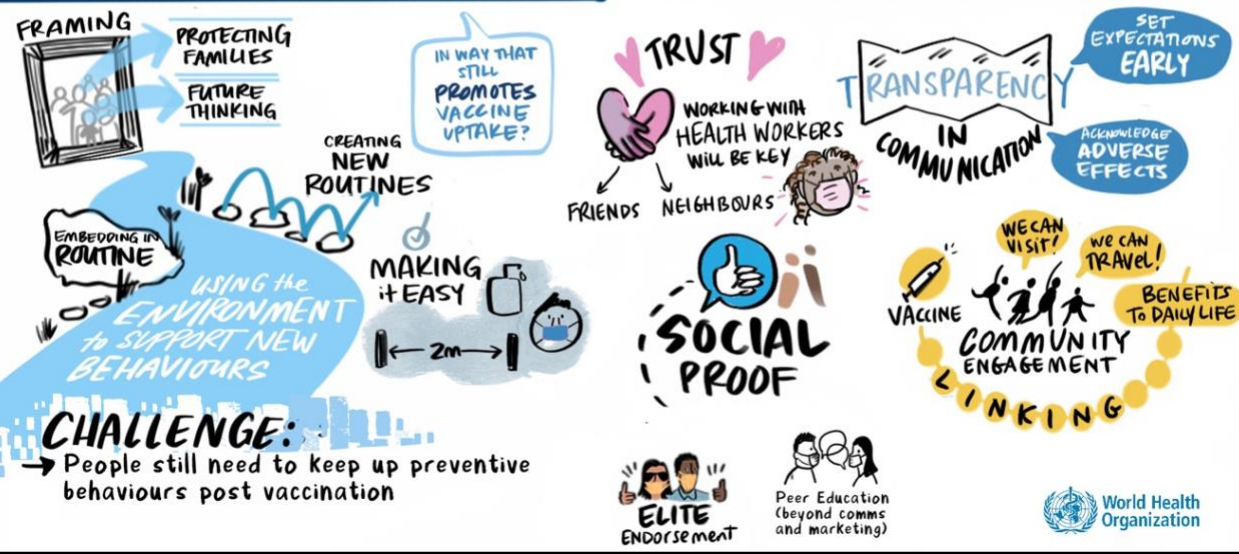


## 1. PROMOTE UPTAKE?



## 2. HOW TO FOREWARN ABOUT RISK COMPENSATION?

## 3. WHAT BEHAVIOURAL INTERVENTIONS CAN PROMOTE UPTAKE for the MOST VULNERABLE GROUPS?







## Please visit:

Our web page at [www.patientsafety.org](http://www.patientsafety.org). Find resources, archived recordings, and a form to share your story or sign up for this newsletter!

And, please like our Facebook Page:

<https://www.facebook.com/patientsafety.org/?ref=bookmarks>

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