

Patient Story



Helene Epstein

HIPPO ON MY CHEST

My son was diagnosed with “life-threatening” asthma in the ED shortly before his third birthday. The pediatrician and allergists confirmed it. Yet, despite ever-increasing doses of preventative medicines — inhalers and pills — his symptoms never improved. I asked the allergists several times to reconsider the diagnosis. I sensed he was ill but lost faith in asthma as the cause. They refused.

Fast forward almost two years: “Mommy, my chest hurts.” We had taught him about ways to describe pain in his chest. Is it a butterfly? Is it a mouse? Is it an elephant?

“There’s a hippo on my chest.”

At the ED, the nurse said, “He’s fine,” she said. “No bronchial sounds, no symptoms.” I asked, “Does your chest still hurt?” “Yes.” The nurse asked, “Do you have a hippo on your chest?” “Yes.” “How *big* is the hippo?” My four-year-old held up his thumb and forefinger an inch apart. “This big.” Brandon’s tiny hippo wasn’t just the product of an imaginative kid. It was a blaring sign that perhaps we were treating the wrong thing.

At Yale Children’s for a second opinion, they were alarmed at the enlarged size of his lungs, like “someone who’s climbed Mount Everest.” No one had ever examined them before. They discovered every sinus cavity was filled with solid material. The nasal passages were completely blocked. The cause? A series of under-treated ear and sinus infections. Instead of a lifetime spent constantly fighting for oxygen, he was healed by a simple 35-day course of antibiotics.

IN THE NEWS



Safe by Design: Reimagining Health Care Around the Prevention of Harm envisions what health care could become if patient safety were designed into every aspect of care from the start. Developed by the Coalition for Advancing Safer Healthcare (CASH), an initiative convened by the **Jewish Healthcare Foundation** and the Pittsburgh Regional Health Initiative, the report introduces the fictional yet realistic Ambition Health System as a blueprint for reimagining health care around the prevention of harm. Drawing on the expertise of more than 100 national leaders in patient safety, healthcare delivery, technology, policy, and patient advocacy, the report challenges health system leaders to move beyond incremental improvements and instead embrace a systems-based approach to creating safer care.

AHRQ halts a large share of its patient safety research grant portfolio. AHRQ, the lead federal agency for patient safety, a key element of healthcare delivery, has discontinued over 100 ongoing grants worth \$229M. These are ongoing grants examining and improving patient safety, the promotion of digital health tools, the measurement of health outcomes, and health disparities research. <https://kffhealthnews.org/news/ahrq-funding-grants-trump-healthcare-safety-research-agency-hobbled/>

CMS has just published its latest **Final Rule for Medicare quality reporting for hospitals and long term care facilities, effective October 1st**. Changes to quality reporting measures are covered primarily in **Section IX (pages 49,9932-50,084)**. New measures address hospital readmission after sepsis, and a new venous thromboembolism outcomes measure. Several existing measures are expanded to include data from Medicare Advantage patients for the first time. There is a continuation of CMS move toward more electronic measures to reduce burden and more patient-reported measures to fill data gaps. CMS also modified the existing Maternal Morbidity measure to require hospitals to name learning

We're thrilled to spotlight PFPS US Champion Helene Epstein, whose generous sharing of resources has enriched this edition of our newsletter. Her ongoing commitment to patient safety and diagnostic excellence keeps patients and families at the heart of everything we do—thank you, Helene!

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Above is "The Eight Characters of a Symptom"
Created by John Ely, MD, MPH; University of Iowa, Carver College
of Medicine
Adapted by Helene M. Epstein | [Patient No More](#)

CMS EVENT: CMS is launching a quarterly stakeholder webinar to share updates on its work to advance prevention, quality, safety, and coverage. Register [HERE](#) for the first one, August 25, 2026 at 11 AM ET.\

National Academy of Medicine *Patient Safety in the Era of AI* initiative: A Listening Session seeking input on draft Priority Actions, their potential impact, possible risks, and opportunities for strengthening. Click [HERE](#)
(Meeting ID: 216 240 628 371 36 | Passcode: 3Rj6yv7o)

Join PFPS US for our World Patient Safety Day Webinar, *The Safe Healthcare System Patients Deserve*. September 17th, 10:00 AM to Noon ET. Register [HERE](#).