Session Objectives

- You will understand the depth of parent and family grief following the death of a child and measures to take to repair relationships
- Significance of diagnostic skills, communication, team work and patient/family partnerships in saving lives
- Absorbing the importance of trust, apology, honesty, empathy and the debt of disclosure owed to the family
- What parents want clinicians to measure and why
- Lessons learned and obstacles overcome
- Families as stakeholders in their child’s care
Justin’s HOPE Project-Story on Film
Changing tomorrows for all of us

http://www.youtube.com/watch?v=3lpDTTruKQ&feature=youtu.be

Jim Conway noted: “So tragic, powerful and beautiful. An exceptional lever for change. Our gratitude only grows, Dale.”

Justin Micalizzi
1989-2001

Jan 15th 8pm: Justin diagnosed with S. aureus ankle infection from orthopedist’s earlier tap

Jan 15th 9pm: “Simple” incision & drainage of Justin’s ankle begins in operating room

Jan 16th 9:20pm: Justin suffers sudden pulmonary hemorrhage and cardiac arrest twice while under general anesthesia

Jan 16th 10pm: Justin transported emergently to the pediatric ICU

Jan 16th 12am-7am: Justin suffers several more cardiac arrests in the PICU. Parents told only that the prognosis is poor

7:30am: Labs, X-rays, brain scan, EKGs performed. More Family & Clergy arrive

7:45am: “No hope” - PICU doctors advise parents to remove Justin from life support

11am: Time of Justin’s death, age 11 years, 7 months, 16 days.

Jan 17, 2001-present: Our search for answers begins...
Justin’s Story
“A Family’s Search for Truth”
by Adrienne G. Randolph, MD, MSc

“On January 15th, 2001, Justin, a healthy 11-year old boy, was taken into surgery to incise and drain a swollen ankle. He was dead by 7:55 a.m. the next morning, leaving behind two grieving and bewildered parents who desperately wanted to know why their son had died. But medical care was to fail them twice – first their son died and then no one would explain to them why. I was one of the consultants, from another Children’s Hospital, contacted by Justin’s parents to review his records and figure out what went wrong.”

~ Adrienne Randolph MD, PSQH Magazine Nov/Dec 06

Questions that remain…
How can these be measured?

- Medication safety-did the bottles look similar?
- Did fatigue or distractions effect the outcome?
- Adequate consideration of staph infection of ankle joint-was he septic? Was black box warning to not use succinylcholine with septic child ignored? Why wasn’t he tested for sepsis?
- Why weren’t ordered labs completed and why were his veins collapsing when they tried? Why didn’t they call in someone more experienced to draw blood. He was caused added distress.
- Did he have an allergic reaction? Are we genetically challenged with an unknown condition?
- Would a chest x-ray, appropriate IV antibiotics or fluids have saved him?
- Should he have had surgery before he was stable and should general anesthesia have been used?
- Did he have a blocked airway?
- Why didn’t anyone communicate what went wrong? We trusted them to know their profession. Didn’t they know or were they afraid to talk to us? Their child did not die...
- Did anything change to improve outcomes at that facility?
Are these indicators or tough questions?

- Who takes the family history & pre-op checklist and how is it shared?
- Do you have a process in place to let parents know how surgery is going?
- How do you measure quality and value?
- Is the child’s safety your first priority? Is safety an embedded culture?
- Do you have a disclosure policy in place if something goes wrong?
- Do you have a safety net in place to provide family or clinician support?
- Is silence or poor behavior accepted as norm?
- Did you ever tell a parent, “These things happen” or medicine is an imperfect science” or “I’ve had lots of kids die in my care”?
- Do you teach communication, teamwork and diagnostic skills and take refresher courses? Do you have mentors?
- Are pharmacists involved in medication safety?
- Are clinicians rushed, distracted, untrained?
- Is honesty seen as an option?
- Do you have a team approach to care?
- Do you have safety huddles?
- Do you have Family Rounds?
- Monitoring how often before and after surgery?
- Is the child and their family at the center of pediatrics?

Measurement

- The WHO Child Growth Standards
  http://www.who.int/childgrowth/en/

Parents want their child’s doctors and nurses to work with them as a team to help Their Child GROW UP
What is measured

- Immunization rates, appropriate use of antibiotics for pharyngitis and upper respiratory infections, depression screening, developmental assessment, hearing/vision screening, prescribing preventive medication for chronic asthmatics, body mass index for obesity.

- Some are measuring patient satisfaction, wait times, courtesy of front desk staff, delays in lab result and x-ray reporting, family assistance programs, informed consents, etc.

- Adverse events — medication errors, missed or delayed diagnoses, treatment errors, diagnostic errors, treatment delays, disclosure policies, family history, check lists adhered to, medication reconciliation, hand-offs safe, monitors working, safety rounds, etc.

Inpatient, Outpatient or Adverse medical Event?
There’s a difference in what parents want measured

- Parents with a child who has a disease will want conditions surrounding that disease measured and managed or cured. (Parents placed more emphasis on having a trusting and positive relationship with their PCP)
  - Diabetes
  - Cancer
  - Rare disease
  - Heart disease
  - Injury
  - Asthma
  - Infections
  - Lung disease
  - Sepsis
  - Hand Washing, Sanitary environment
  - Patient and Family Centered Care
  - Shared decision making

- Parents who had a child injured or die as a result of an adverse medical event want the conditions surrounding the event measured and learned from. (Parents’ trust has been broken—focus on behaviors and systems)
  - Medication errors
  - Anesthesia complications
  - Lacking Communication and Transparency
  - Failure to monitor or rescue
  - Wrong diagnosis
  - Wrong procedure
  - Continuing education of clinician
  - Fatigue or distraction, Alcohol/Drug abuse of staff
  - RCA needed with their involvement
  - Surgical complications
  - Disease specific measures—what was child being seen for before the event
  - Patient and Family Centered Care
  - Ethics
As many as 160,000 hospitalized patients die or suffer a significant, permanent injury each year because health care providers either misdiagnose a condition, arrive late at a diagnosis, or miss the problem completely, according to a report by Newman-Toker and colleagues in the August 2013 issue of BMJ Quality and Safety in Health Care.

― Marlynn Wei MD/JD, Yale

"Despite the difficulty in changing actual behavior, there may be symbolic importance and moral worth for medical schools to demonstrate their normative commitments, encourage apologies as the virtuous thing to do, and to put increasing moral pressure against the silence that surrounds mistakes."

― Marlynn Wei MD/JD, Yale
What we needed the most...

Kindness is a language never forgotten

"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."  - Maya Angelou

"We are truly social animals who need to know that someone cares. That is not a weakness; but, a basic need like eating and breathing.”  ~ Col. John H. Chiles, M.D

Partnering with Healthcare

Justin’s HOPE Project
Making a Difference

"The world is a dangerous place to live; not because of the people who are evil, but because of the people who don't do anything about it."

~ Albert Einstein

Our Journey to Date...NJ HEN ADEs

<table>
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<th>Adverse Event Area</th>
<th>Baseline</th>
<th>Current</th>
<th>% Change</th>
<th>AHA/IMED Cost per Incident</th>
<th>BHQ Report Cost per Incident</th>
<th>Incidents Prevented</th>
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Medication Safety

"We have made our CMS marker and decreased ADEs > 40%."
Education: One & Only Safe Injection Practices Campaign

- Our NY One & Only workgroup consists of many clinicians & patients and families who all collaborate with a common goal
The Heart of Health Care: Parents’ Perspectives on Patient Safety

Pediatric Clinics of North America


- Authors: Dale Ann Micalizzi, Marie M. Bismark

- Abstract
  Behind the wall of silence in health care are the unanswered questions of parents who have experienced harm at the hands of their caregivers. In an industry where information and communication are crucial to quality, parents’ voices often go unheard. Although that has begun slowly to change, providers could benefit from following the HEART model of service recovery, which includes hearing the concerns of patients and their families, empathizing with them, apologizing when care goes wrong, responding to parents’ concerns with openness, and thanking the patient and family.

- Keywords: Patient safety, HEART model, Service recovery, Medical error, Patient harm, Healthcare quality

- Where parents can become allies rather than adversaries in the quest for safer care.

Objectives of our Chapter

Objective 1: Communicate the experience of patient harm from the perspective of parents whose children suffered or died as a result of failures in the health system.

Objective 2: Identify, with case examples, the ways in which families of injured patients can - and do - drive improvements in care delivery, consent processes, open disclosure, and person-centered care

Objective 3: Promote partnerships between providers and families as a source of insight, innovation, and strength in the patient safety endeavor.

Heart Service Model-used by those who seek to resolve problems by putting the needs of the affected person first. Cleveland Clinic: http://my.clevelandclinic.org/patient_experience/what_we_do.asp and Duke University and others.

- Hear
- Empathize
- Apologize
- Resolve
- Thank

Time to Care How To Love Your Patients and Your Job by Dr. Robin Youngson
Creator of Hearts in Healthcare
Ways in which parents can contribute to patient safety

- Education and information
- Advice and support
- Empowerment
- Medico-legal action
- Research and analysis
- Writing and presenting
- Technology and design
- Funding
- Policies and standards
- Governance
- Legislation and regulation
- Art and culture

- Grand rounds
- Medical student teaching
- Curriculum design
- Face-to-face support groups
- Online support groups
- Websites
- Workshops
- Family rounds
- Advocacy
- Complaints
- Lawsuits
- Inquiries
- Root cause analyses
- Surveys
- Research
- Collaborations
- Editorials
- Conference presentations
- Articles and books
- Smart phone applications
- Patient education tools
- Fundraising
- Scholarships
- Foundations
- White papers
- Accreditation standards
- Advisory Councils
- Directories
- Lobbying
- Drafting bills
- Music
- Gardens
- Art

Paul Sharek, MD, MPH
Lucile Packard Children’s Hospital

- Harm occurs at high frequency in children’s hospitals
- Translating high reliability concepts into health care will be challenging, but will move us to ultrasafe care
- Parents are crucial partners in the transformation from patient safety mediocrity to high reliability


Join us at PIPSQC: http://www.pipsqc.org/ResourceCentre/Presentations.aspx
Partnering With Parents to Save Children’s Lives

By pipsc blog on Monday, April 15, 2013 Author: Dale Ann Micalizzi

http://tinyurl.com/h6qjve

I was recently reminded of a team building activity, usually for youth, referred to as the “Trust Fall.” You’ve heard of it, I’m sure. It’s where you place your arms across your chest, close your eyes and free fall backwards into the interlocking arms of your friends or team. Some may be reluctant to be the one falling or the one expected to catch. But the goal of the exercise is to build harmonious team spirit and trust. You can depend on me and I can depend on you… no matter what. A sports team often feels this deep connection and bond. My hope is for hospitals and healthcare organizations to feel that partnership and trust with their staff, patients and their families.

[...] Read More »

Comments (9)

Do you have a safety net in place at your facility? Can we measure harm so we can improve upon healing?

- When an adverse medical event occurs
- When a child is diagnosed
- When a child dies
- When a sibling dies
- When a teen is alone
- When counseling/support group is needed
- When we learn bad news
- When surgery is needed
- When an amputation is needed
- When life support is removed
- When a parent dies
- When no one visits
- When the insurance and money are gone
- When depression sets in
- When the child is disabled
- When God is needed
- When a friend is needed
- When medical ethics is in question
- When answers are needed in order to carry on
  - When child care is needed
  - When transportation is needed
  - When medical supplies are needed
  - When coordination of care doesn’t exist
Specific Area(s) of Interest: Pediatric Patient Safety, compassionate Patient/Family Centered Care, Transparency in Medicine, Med Education

Barb Farlow
Website: Justin’s HOPE Healthcare Blog

Specific Area(s) of Interest: Tracheostomy Safety, Handovers, QI Recruitment and Education.

Biography

Medical interventions for children with trisomy 13 and trisomy 18: what is the value of a short disabled life?

Email: jpadilla43@live.com

hannah.h.zhu@gmail.com

Pediatric Patient Safety Advocate and Consultant

JD, PIPSQC Ambassador Assistant Lead

Dr. Tricia Pil
Website: Babel: The Voices of a Medical Trauma

Specific Area(s) of Interest: Patient Safety, Quality Improvement, Patient Engagement, Improving Patient Communication, Grief Support

Email: tricipil@chsc.edu

Website: "Babel: The Voices of a Medical Trauma"
Research: Measuring and Learning from Our PIPSQC Surveys

- PIPSQC Adverse Medical Event Survey for Families
- PIPSQC Family Assistance Program Survey for Families
- PIPSQC Patient Survey for Children and Teens
- PIPSQC Family Assistance Program Survey for Healthcare Professionals

To be released soon on the PIPSQC and Justin’s HOPE Project Websites

Lessons Learned from Parents in Pediatrics

- Medication reconciliation
- Family history
- Child’s wants, needs and preferences
- Supporting is necessary
- Compassion is a must
- Patient safety and quality are vital
- Simple things matter
- Parent empowerment needs reinforcement
- There is no greater love than that of a parent
- Parents know their child best
- Parents can be the provider’s eyes
- Having a sick child is hard—it affects the entire family
- Parents can handle much more than you think… including the truth
- Most parents are reasonable and learn quickly
- Parents have a passion to find a cure
- Listening is necessary
- Patience is required
- Parents want to help
TED Talk Stefan Larsson: What doctors can learn from each other

http://www.ted.com/talks/stefan_larsson_what_doctors_can_learn_from_each_other.html

“We are bringing together leading physicians and patients to discuss disease by disease what is quality, what should be measured… By measuring value in healthcare we will bring about the revolution… that will put the patient at the center.”

We need Innovation and your help!

“Quality Improvement Means Making it easy for people to do things right…and hard to do things wrong.”
Justin Micalizzi Memorial Institute for Healthcare Improvement Forum Scholarships

The Justin Micalizzi IHI Forum Scholarship is for health caregivers who are committed to pediatric patient safety and providing a safe healthcare environment for their patients and families. In partnership with The Task Force for Global Health and IHI, we have awarded 19 IHI Forum Scholarships to date to the most amazing healthcare providers working with vulnerable populations! Please welcome this year's winners to the Forum!


*Applications available each year (as funds permit) found on IHI Forum Enrolment tab
*Donations at The Task Force For Global Health Website

Why I remain an advocate for children and families and pediatric patient safety

Our grand daughter Isabella

Thank you for all you do to care for our children, to keep them safe and to help them grow!
A New Era: Thank you for joining us
We NEED You!

It is most certainly a time in history for an era of compassion, integrity and safety. Let’s begin with medicine and blaze the trail. The others will follow when they see our success.

– Dale Ann Micalizzi Pulse Magazine

Justin’s HOPE Project
The Task Force for Global Health (Child Survival and Development)

Justin’s HOPE healthcare blog http://justinhope.tumblr.com/
and Justin’s HOPE Project website http://www.taskforce.org/our-work/proj
Follow me on twitter @JustinHOPE
Compassion in Healthcare-The Heart of Healing facebook group

Healthcare Openness Professionalism Excellence
– An era of Compassion –