Pediatricians Partnering with Patients and Families to Save Lives

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Justin’s HOPE Project at The Task Force for Global Health (Child Survival and Development)
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PIPSQC “Making Health Care Safer for Children” M23
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.”

~PSQH Magazine Nov/Dec 06
What we received from the Physicians, Hospital Administration, Risk Mngt. and their Attorneys:

SILENCE
The Grief Process

- Shock, numbness, sadness, regret, guilt, disbelief, terror, despair, anger, physical pain and loneliness are common. Few people can understand how deeply a bereaved parent hurts unless they have been there. The pain and sadness is always with us.

- It was our job to keep our child safe. If we don’t know what happened, we inevitably blame ourselves for having failed in our duty as parents.
Will You Help Me Find the truth?
Who is in charge?

WHY?
Etiologies:

- Pulmonary or air embolus
- Septic-toxic shock/Severe Sepsis/Septic arthritis
- Pneumonia-pre op x-ray would have saved him
- Aggressive irrigation causing embolus/cardiac arrest
- Medication over dose
- Malignant Hyperthermia
- ET tube improper insertion/blocked airway (kinked tube/muscular reaction)
- Succinylcholine (muscle relaxant) hyperkalemia
- Microscopic abnormality of Mitral Valve/Long QT Syndrome
- Joules of electricity too high
- Tourniquet too tight-vitals different in extremities
- Allergic reaction
- Anesthesia machine malfunction, alarms turned off
- Failure of critical thinking and team work
- Constellation of errors before and after event
The truth will set you free...

- 9 yrs
- 9 months
- 4 days later

The letter that took me 10 yrs to write...
http://justinhope.tumblr.com/post/10380571733/the-letter-that-took-me-ten-years-to-write
What Patients and Families want and need following an adverse medical event

- Immediate unbiased investigation with complete disclosure
- To be listened to and taken seriously. Don’t protect us. Don’t lie to us. Don’t diminish our need to know.
- Practices and systems changed to prevent a similar event
- Standards of care mandated with regulatory systems in place and someone in charge
- Respect, empathy, apology
- Medical bills dismissed
- Justice
- Some want partnerships with healthcare providers and some are too hurt to partner—be gentle with them.
Become active participants in the patient safety & quality movement—partner with patients and families

- Thank you for showing up here!
- See IHI WIHI, Open School, various other IHI opportunities
- Sign the pledge at HHS Partnership for Patients and become involved
- Listen to patient and family stories
- Ask patient/families what they need and how you/they can help
- Practice and teach diagnostic skills
- Hire those with values
- Be a leader
- Listen to your staff
- Ask your team what they need and how they can help
- How can you improve communication skills for your team?

- See Dr. Tony DiGioia’s work Patient- and Family-Centered Care Methodology and Practice
- See IHI White Paper: “Respectful Management of Serious Clinical Adverse Events”
- “What happens when things go wrong?” our paper in Peds Anesthesia
- See PIPSQC
- See Planetree
- See TeamSTEPPS
- See Henry the Hand
- See Parent to Parent/Family Voices
- Follow AHRQ PSNet What’s new this wk?
- AHRQ M&M
- Follow me on twitter @JustinHOPE or my facebook group “Compassion in Healthcare-The Heart of Healing”
Building Community Health with value(s) Together

Own your block of care but then connect it to others and watch what is possible.
Ways to invite patients and families in to help

- Grand Rounds
- Conferences
- Work groups
- Speaking engagements with patients/families
- Root Cause analysis
- Medical student presentations
- Published articles
- Legislation
- Speak up campaign
- Media involvement
- Care manuals
- Surveys
- Websites
- Social media

- Connections
- Patient family advisory counsels
- Rewriting policies
- Videos
- Research opportunities
- Grant writing and submissions
- Fundraising
- Communication tools
- Check lists
- Tool kits
- Purchase new needed equipment/supplies
- Write a book
- Share journal publications
Ways to invite patients and families in to help

- Family rounds
- New office design/PICU ambiance
- Hospital improvements for families
- 24/7 visiting hours
- Pet therapy
- Music therapy
- Art therapy
- Children w/disabilities concepts for improvements
- Internet access, helpful apps
- Involving medical residents
- Involving pharmacy students
- Involving nursing students
- Phone or email trees
- Seminar on collaboration

- Patient/Family board members
- Genetic testing programs
- Advocacy
- Newsletters
- Support groups
- Grief or end of life support
- Clergy involvement
- Fighting pediatric poverty/hunger
- Preventing obesity
- Preventing child abuse
- Education programs
- Parenting programs
- Hand washing—See Henry the Hand
- Campaign for best practices
- Safe injection practices
- Community outreach
- Rare disease support/research
- Caring Bridge
What you Should Tell Prior to Surgery Requiring Anesthesia

(Dr. Henry Rosenberg of MHAUS & Dale Ann Micalizzi of Justin’s HOPE)

- Describe when the patient last consumed any liquid and solid food. What was it?
- Provide accurate information, including dose and frequency of all medications that are being taken, including antidepressants, vitamins, and diet pills, performance enhancing and herbal medications.
- Report all allergies and adverse reactions to (for example): medications, latex, and foods.
- Describe the use of alcohol and/or recreational drugs, as well as how often/how much.
- Relate whether the patient is taking prescription drugs illegally. What are these medications and their dose and frequency of use?
- Ask as a reminder if any pre-operative testing (including ordered labs, x-rays, urinalysis etc.) will be completed, reviewed and acted-upon prior to surgery.
- Provide the names and contact information about each of the patient’s physicians to the surgical/anesthesia team.
- Tell your surgical/anesthesia team about any recent illness symptoms, including an elevated temperature or flu-like symptoms in the week or day prior to the procedure. Tell them about any recent nausea or diarrhea.
- Describe any recent injury or surgeries.
- Provide full information about any diagnosed conditions and their treatments, including any history of asthma, heart problems or autoimmune deficiency.
- Describe any problems that you or family members have experienced during or after anesthesia, including any history of muscle weakness or severe muscle pain after anesthesia.
- Describe any personal or family history of brown or dark urine following anesthesia and surgery, or occurring spontaneously with exercise.
- Describe any personal or family history of heat stroke.
- Describe any personal or family history of muscle disorders.
- Double check that the correct site is marked at time of surgery before patient enters the OR and verify that they use the WHO safe surgery checklist at their facility.
What you Should Ask Prior to Surgery Requiring Anesthesia
(Dr. Henry Rosenberg of MHAUS & Dale Ann Micalizzi of Justin’s HOPE)

- Who will provide the anesthesia and what is their background? Anesthesiologist? Nurse Anesthetist or Anesthesia Assistant? Sedation Nurse?
- Is the facility licensed by the State?
- Is the facility accredited by the Joint Commission or other accrediting agency?
- Is there an anesthesia machine that is used? If so, who maintains the machine?
- Are patients undergoing general anesthesia monitored by ECG (electrocardiogram)? Is Oxygen saturation measured by using a pulse oximeter? Is exhaled carbon dioxide measured? Are the concentrations of anesthesia gases monitored?
- Is body temperature measured during anesthesia? How?
- Is there a defibrillator present?
- Have those that will provide my anesthesia/sedation satisfactorily completed an Advanced Cardiac Life Support course within the last two years?
- Does the facility perform blood tests (“blood gases” and electrolytes) on site?
- Is there a recovery area and is it staffed by a nurse?
- Is there a written protocol for managing Malignant Hyperthermia?
- Does the facility have 36 vials of dantrium/dantrolene immediately available?
- Does the facility have a cart or other location where additional supplies are kept to manage a case of MH?
- Does the facility perform drills to prepare for MH each year? Have all current employees been trained?
- What Hospital is back-up for the ambulatory center?
- Is there a written protocol for transfer to a hospital in case of emergency?
- How long does it take to transfer?
- Are my records maintained by the facility? For how long?
What would be the one thing that you would change in healthcare that you know would save lives?

- Marie Bismark (MD, JD) wrote: "Teaching doctors that it's OK to say these five simple phrases: (1) "I don't know but I'll try to find out for you" (2) "I'm tired and I need a break" (3) "I need some help with this" (4) "I'm sorry I made a mistake" and (5) "I'm concerned about my colleague.""

- My answer: Rapid, honest, compassionate disclosure following adverse medical events and then learn from them to safeguard the next child.

- How would you answer my question?
Complaints from pediatric parents:

- No communication-keep me in the loop
- I deserve to know what happened to my child
- Perceived arrogance-all of my questions are important
- Sepsis-children being sent home from peds office or ED many times before sepsis dx
- Tubing connections wrong
- Medication errors
- Pre-op orders not followed
- Sloppy medicine-EMR will help
- Allergic reactions went undiagnosed—I told them family hx
- No monitoring in OR (i.e., temp, pulse ox, digital recordings)
- Hospital/Dental acquired infections
- Unsafe injection practices
- Docs not thinking, “What else could it be?”
- Temp staffing or overworked resident/nursing staff
- Team work not apparent-docs not talking with each other
- No one asked me to be their partner in care—I know my child best
- Don’t treat me like the child
Save a Child’s Life

STOP and Listen

to the
Patient & Family
and the Pediatrician
Carefully!

Created by Justin’s HOPE Project at The Task Force for Global Health
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
Justin Micalizzi Memorial
IHI Forum Forum Scholarship
Winners

Justin Micalizzi 2008, 2009 & 2010
IHI Forum Scholarship Winners!

Congratulations to our
2011 IHI Forum Scholarship winners:

Kelly Garrison
Nora Dackiewicz
Rachel Wang
Patient Stories and Mothers’ Quests

- Tubing misconnections- *Chloe*
- Malignant Hyperthermia and Missed diagnosis- *Vincent*
- Rare Diseases and Pediatric Partnerships- *Kirsten*
- Unsafe pediatric injection practices
Chloe’s Story

Chloe was born ten weeks premature. During her NICU stay, the G-tube line that delivered her feedings into her stomach was attached to her IV Line. This caused fortified expressed breast milk to be infused into her bloodstream and her entire body. Due to this error, she was on life support for three days. She suffered DIC, seizures, as well as numerous life-threatening medical issues. She miraculously survived. The hospital administration and medical staff were very upfront about the error from the start. We were thankful for their open communication during the event.
Vincent’s Story
June 27, 2003 – June 14, 2010
Malignant Hyperthermia awareness

- Vincent was a normal healthy 6 year old boy who went from full of life one moment to having muscle cramps, fever & tachycardia the next. Vincent died in less than two (2) hours from a Fatal “Awake” Episode of Malignant Hyperthermia just 2 weeks before his 7th birthday, and we have yet to understand what triggered this in him.

- As the research continues and new discoveries come to light, it is my hope that the education and training of medical professionals expands. The ER was not prepared for an “awake” MH episode. Even with the symptoms I provided the staff, their differential diagnoses did not include the possibility of anything other than infection. When the doctor in the ER administered succinylcholine to intubate Vincent, if he/she was advised of the muscle rigidity Vincent was experiencing when he came home and the subsequent symptoms of tachycardia, hyperkalemia, increased CO2, perhaps a connection could have been made. If there was any chance of saving Vincent, that chance was lost once they administered succinylcholine.

- Over the past year I have talked at staff meetings at the local hospitals, all of the EMT staff in Lake/Sumter counties, and UCF Nursing Program students.

- It is my hope that in Vincent’s name we can continue to raise awareness regarding MH among emergency medical professionals and help to establish protocols for EMTs and ER staff. If there’s a fever, it doesn’t necessarily mean there is an infection. There should be a range of differential diagnoses. One should never become complacent in their medical training.
Kirsten’s Story
Rare Diseases and Pediatric Partnerships

- My daughter Kirsten was born with Pierre Robin sequence. She could neither breathe nor swallow. She was at constant risk of experiencing an obstructive event and dying, especially in her sleep. She slept 22 hours a day. She had a lip-tongue adhesion at a few weeks but it did not work because her tongue still fell back and blocked her airway. After six months she received a tracheotomy. The first year she was tenuous at best and I essentially ran a 24/7 ICU in my home with no help and two boys age 3 and 1.5 when she was born.

- Our wonderful pediatrician, Wayne Cannon, called me just about every morning that year. He asked how we were handling the financial burden. When Kirsten developed a thick ring of scar tissue every few days around her g-tube site, the surgeon told me I was supposed to keep burning the excess flesh off. I couldn’t burn my own baby! Dr. Cannon arranged for me to bring her in to clinic every few days and they did it for me. They never charged. When Residents, unfamiliar with Kirsten’s birth defect or the concept that a Mom must sleep at least every few days would send us home from the ED, we were set up as direct admit. When I could not go on (I had no nursing care and a now former non-helpful spouse), I would call the clinic and they would admit her so someone else could be vigilant and I could get a night’s rest. Dr. Cannon has continued to advocate for and manage Kirsten’s care. She has continued to have complex/chronic issues mostly associated with her airway. Kirsten is now 18!

Slide by Lisa Morrise
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Parents' horror as they are told to test their infants for HIV after flu vaccine mix-up

By DAILY MAIL REPORTER
Last updated at 10:59 PM on 13th April 2011

The parents of children vaccinated at a Colorado clinic have been told to test their infants for HIV after a mix-up by a medical assistant.

Vaccine syringes were shared between children receiving their paediatric flu shot, the Med Peds Clinic of Fort Collins has revealed.

Now terrified parents are being told to test their children for blood-borne diseases such as HIV, Hepatitis B and Hepatitis C.
Thank you for fighting for the children!

- My sweet grand daughter Isabella
Presentations, Interviews and Partnerships:

Publications and Research Support

- Zimmerman, Rachel *Doctors’ New Tool To Fight Lawsuits: Saying 'I'm Sorry'* Wall Street Journal May 18, 2004 http://www.mc.vanderbilt.edu/centers/cppa/wallstreet.htm (Contributor)
- Wei, Marlynn *Doctors, Apologies, and the Law: An Analysis and Critique of Apology Laws* Yale Law School/Yale School of Medicine 2006 http://digitalcommons.law.yale.edu/cgi/viewcontent.cgi?article=1030&context=student_papers
- Remaking American Medicine PBS Special 2007 (Contributor)
- Institute for Family-Centered Care/Institute for Healthcare Improvement *Partnering With Patients and Families to Design a Patient-And-Family Centered Health Care System 2008* (Expert Panel)
- Shapiro, Eve *Putting the CARE in Health Care* (Compassionate Care Personified) The Joint Commission Resources book 2009 (Contributor)
- King, Sorrel, *Josie’s Story* 2009 (Consultant and Contributor) Grove Atlantic Publisher
- Hearst Publication series on *Dead by Mistake* 2009 (Consultant)
- Olson, Barbara, *Hope and the Power of Parents* Medscape Nov 2009 (Contributor)
- DerGurahian, Jean, *From tragedy to advocacy* Modern Healthcare Magazine Sept. 7 2009 (Consultant and Contributor)
- DerGurahian, Jean, *Changing course* Modern Healthcare Magazine Nov. 2, 2009 (Contributor)
- Informed Choice by Marie Bismark MD, JD and Dale Ann Micalizzi published 2011 Health Issues Journal
Thank you!

Special thanks to ALL of the physicians from across the US and abroad who cared enough to help a grieving stranger understand. I had to search for them but I found them in abundance. They were my teachers, my confidants, my friends. They listened to my heart and shared theirs. They are the reason why I know compassion, integrity and safety really do exist in medicine and we can do better. I will be forever grateful. They know who they are~

- Ark drawing by Erika G. age 7
  (Completed for Justin’s HOPE Project)
Justin’s HOPE Project
The Task Force for Global Health (Child Survival and Development)
http://www.taskforce.org/our-work/project

Justin lives forever in my heart

Healthcare Openness Professionalism Excellence
~An era of Compassion~