Patients as Part of the TEAM to Prevent Diagnostic Error

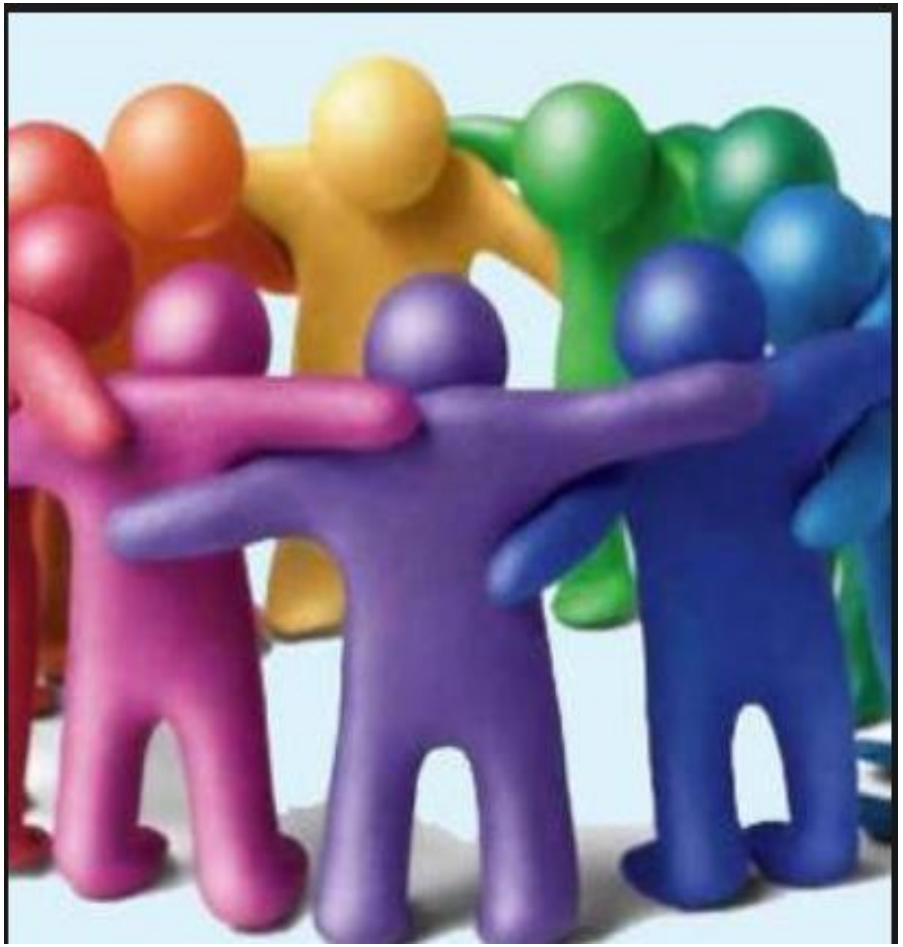
"What Ifs"

Susan Sheridan, MIM, MBA, DHL
Director, Patient Engagement
Society to Improve Diagnosis in Medicine (SIDM)

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

To Err is Human

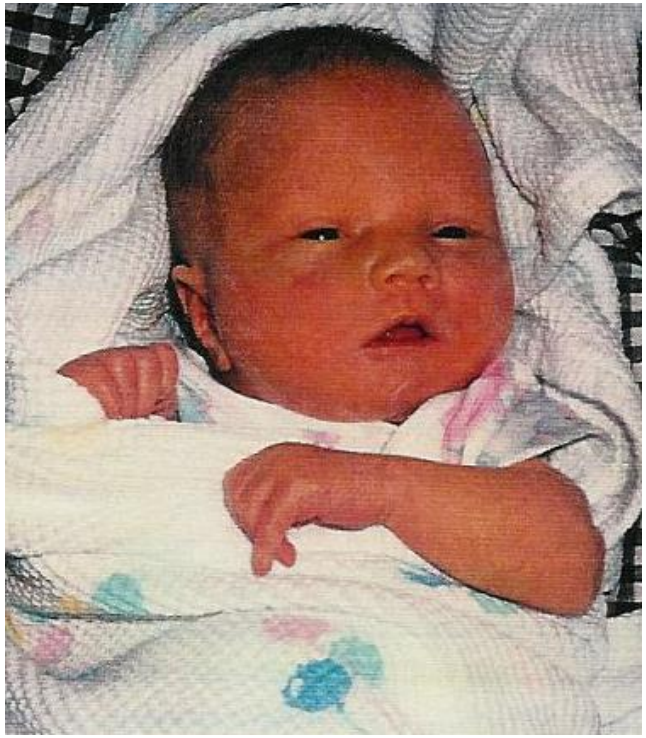
Preventing Diagnostic Error - It's a Team Sport



- Diagnostic Level
- Healthcare Organization Level
- Healthcare System Level

Diagnostic Level

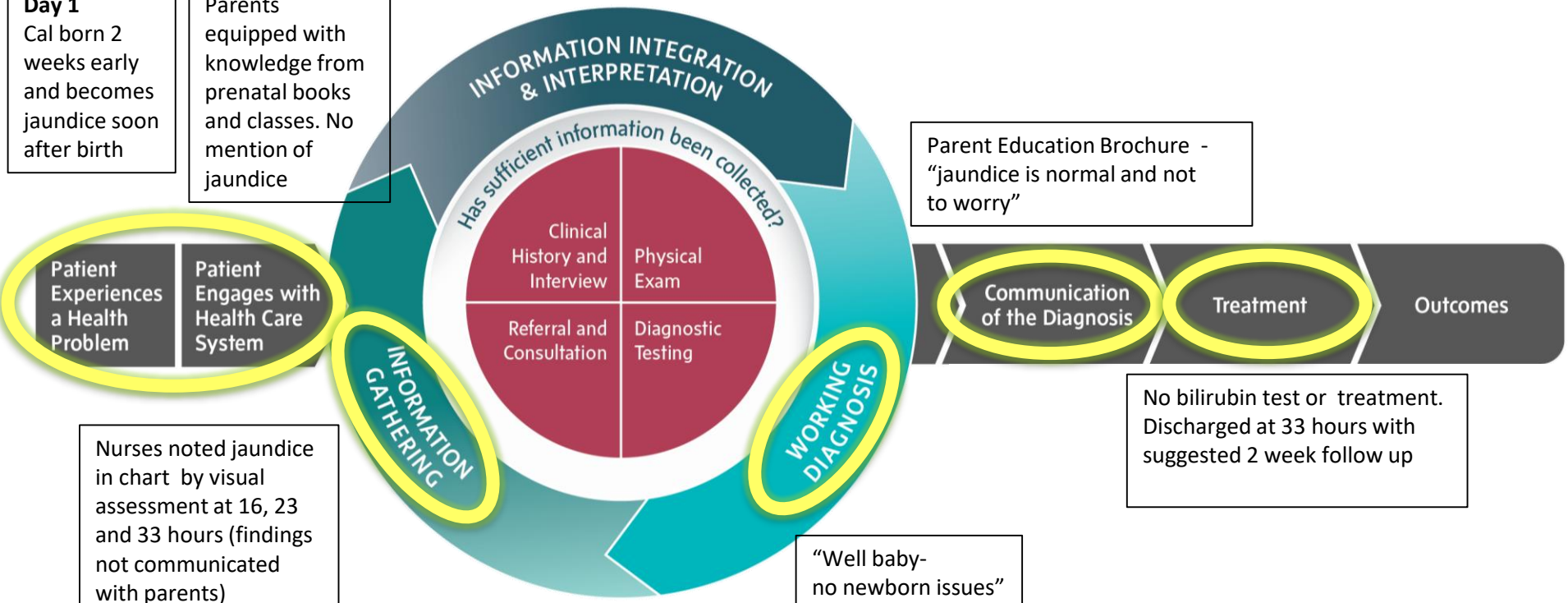
Case Study #1 - Cal Sheridan: Failure to diagnose severity of newborn jaundice



Cal's Diagnostic Journey - Day 1

Day 1
Cal born 2 weeks early and becomes jaundice soon after birth

Parents equipped with knowledge from prenatal books and classes. No mention of jaundice



Parent Education Brochure - "jaundice is normal and not to worry"

Nurses noted jaundice in chart by visual assessment at 16, 23 and 33 hours (findings not communicated with parents)
No bilirubin/jaundice test.

"Well baby- no newborn issues"

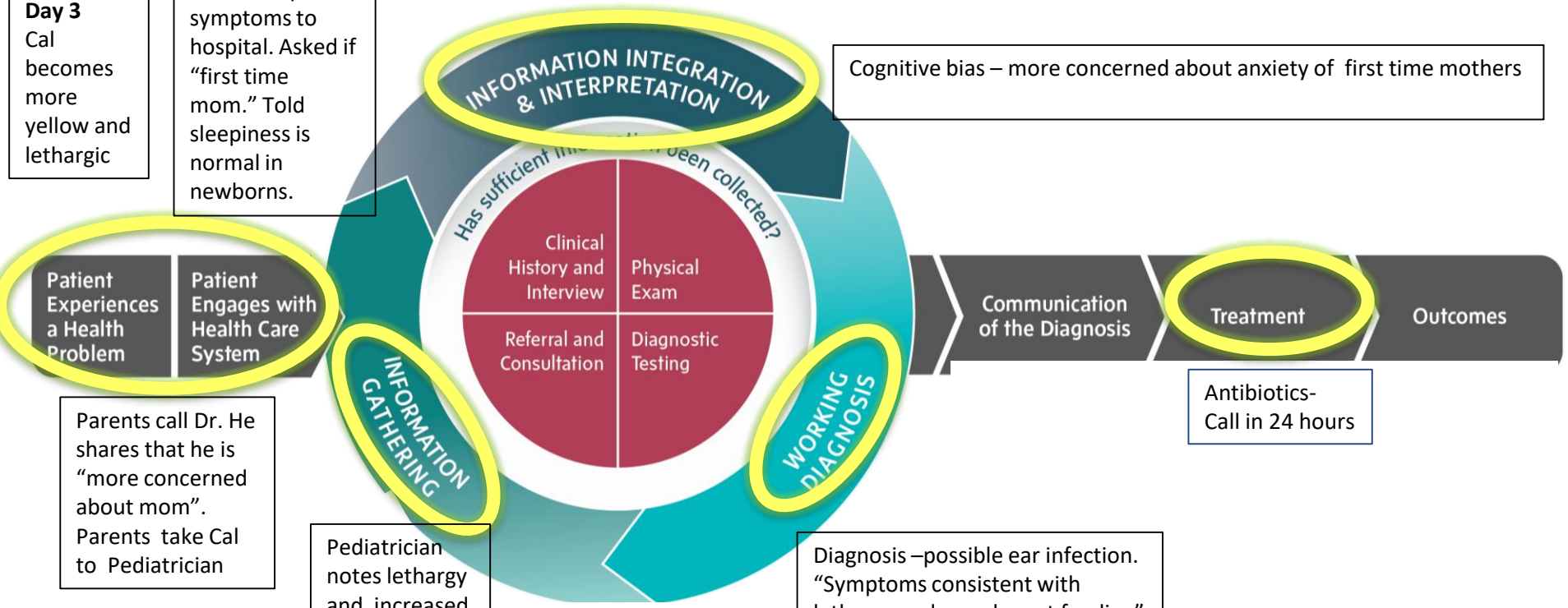
No bilirubin test or treatment. Discharged at 33 hours with suggested 2 week follow up

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

Cal's Diagnostic Journey – Day 3 (Outpatient)

Day 3
Cal becomes more yellow and lethargic

Parents report symptoms to hospital. Asked if "first time mom." Told sleepiness is normal in newborns.



Cognitive bias – more concerned about anxiety of first time mothers

Parents call Dr. He shares that he is "more concerned about mom". Parents take Cal to Pediatrician

Pediatrician notes lethargy and increased yellow color by visual assessment. No bilirubin test ordered

Diagnosis –possible ear infection. "Symptoms consistent with lethargy and poor breast feeding"

Antibiotics- Call in 24 hours

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

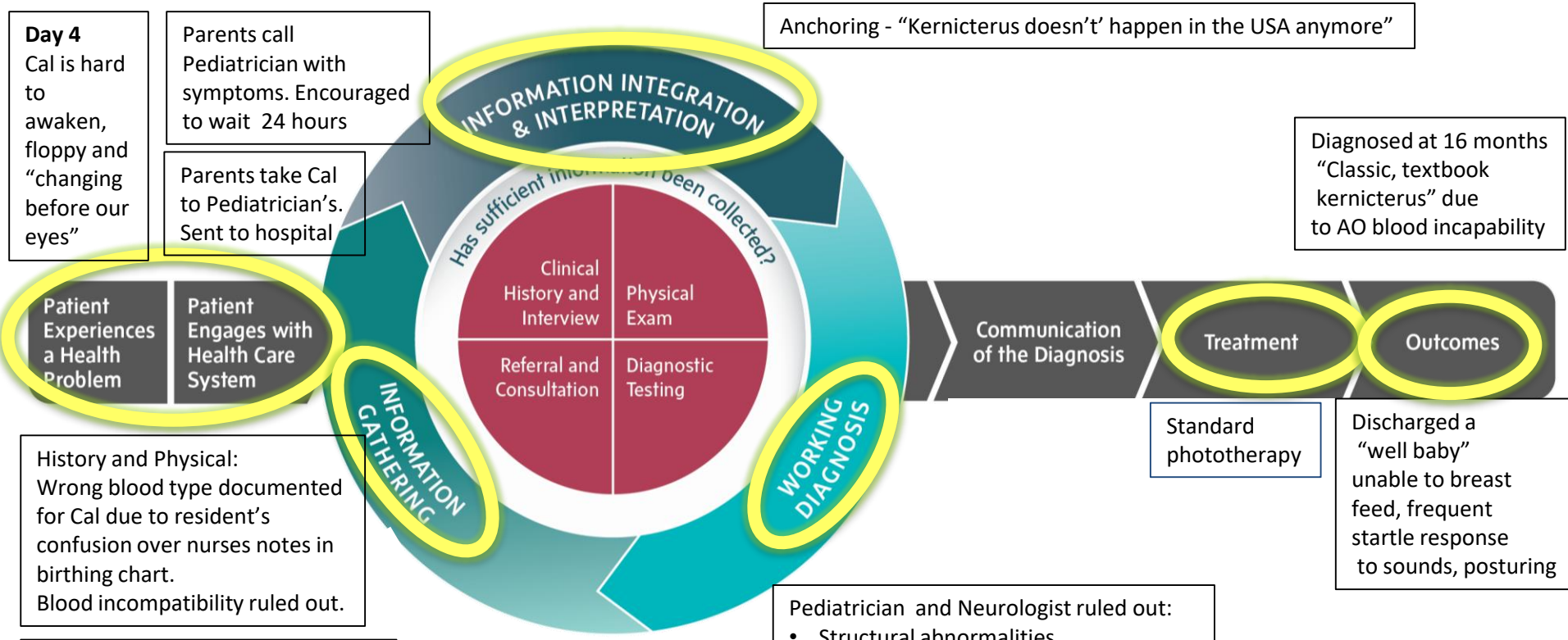
Cal's Diagnostic Journey – Day 4 (Readmission)

Day 4
Cal is hard to awaken, floppy and "changing before our eyes"

Parents call Pediatrician with symptoms. Encouraged to wait 24 hours

Parents take Cal to Pediatrician's. Sent to hospital

Anchoring - "Kernicterus doesn't' happen in the USA anymore"



Diagnosed at 16 months "Classic, textbook kernicterus" due to AO blood incapability

Standard phototherapy

Discharged a "well baby" unable to breast feed, frequent startle response to sounds, posturing

History and Physical:
Wrong blood type documented for Cal due to resident's confusion over nurses notes in birthing chart.
Blood incompatibility ruled out.

Bilirubin test: 34.6 mg/dcl-highest ever recorded at that hospital.
Test repeated twice for accuracy
No referral to NICU

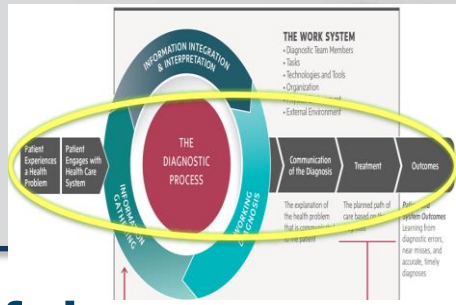
Pediatrician and Neurologist ruled out:
- Structural abnormalities
- Meningitis

Kernicterus never in differential diagnosis

Dr's. notes:"Opisthotonis and high pitched cry" - requested Neuro consult per parents request
MRI: increased intensity in Globus Pallidus - not communicated to parents

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

“What If” Engagement



What if I had been empowered as a member of the “diagnostic team”?

- ……and had been informed about the dangers of severe jaundice, the availability of a bilirubin test, the risk factors, the symptoms to report and how to escalate to get an accurate and safe diagnosis?

- ……..and the symptoms I was reporting of lethargy, floppiness and deepening yellow color had been integrated into the “information gathering” to help form the diagnosis?

- ……..and had access to electronic health records (EHRs), including real time clinical notes and diagnostic testing results, to enable me to participate in the diagnostic process?

“What If’s” – Information Gathering

What if others had been empowered as members of the diagnostic team?

- ….and the lab technician and radiologist had been part of the “diagnostic team” and had 2 way communication with the treating clinicians and Pat and me?

- …..and the nurses had been considered “frontline” diagnostic team members and were authorized to order a bilirubin test?

Health Care System Level
Case Study #1

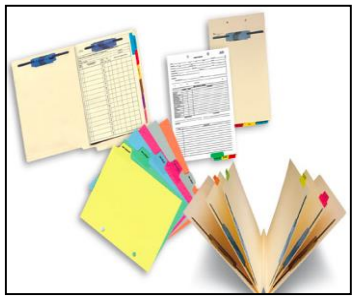
Turning "What Ifs" into Health Care Systems Change

Parents of Infants and Children
With Kernicterus

Researchers
Vinod Bhutani and Lois Johnson

P.I.C.K. Teamed with Researchers: Developing the Evidence

Registries:
Patient donated data



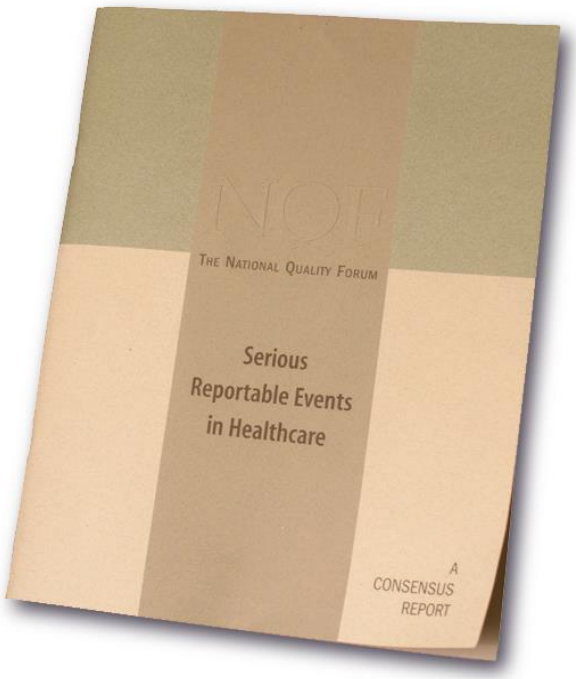
Focus Groups:
HRSA funded

Comparative Research:
HCA donated
Data sets of 250,000 neonates

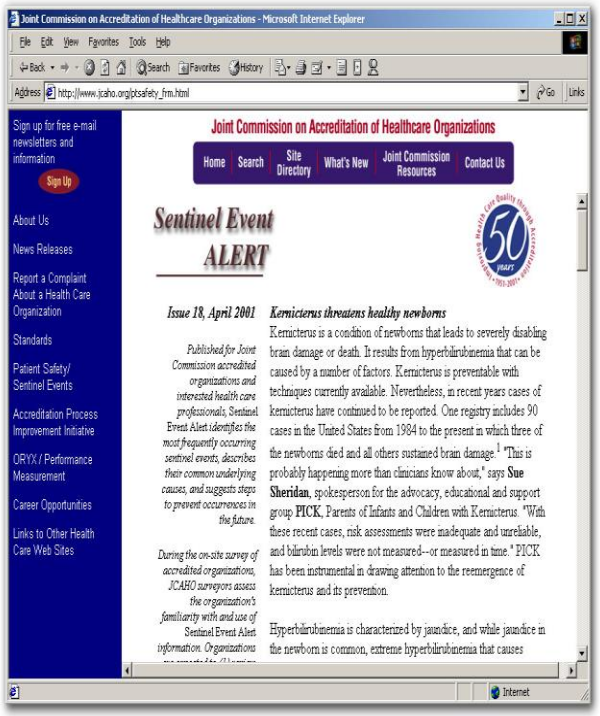
Survey:
CDC funded

P.I.C.K. Teamed with Policy Makers

The National Quality Forum



The Joint Commission



PICK Teamed with AAP Guideline Developers

"In addition to clarifying certain items in the 2004
AAP guideline, we recommend universal predischarge bilirubin screening using total serum bilirubin (TSB)
or transcutaneous bilirubin (TcB) measurements" (2009)

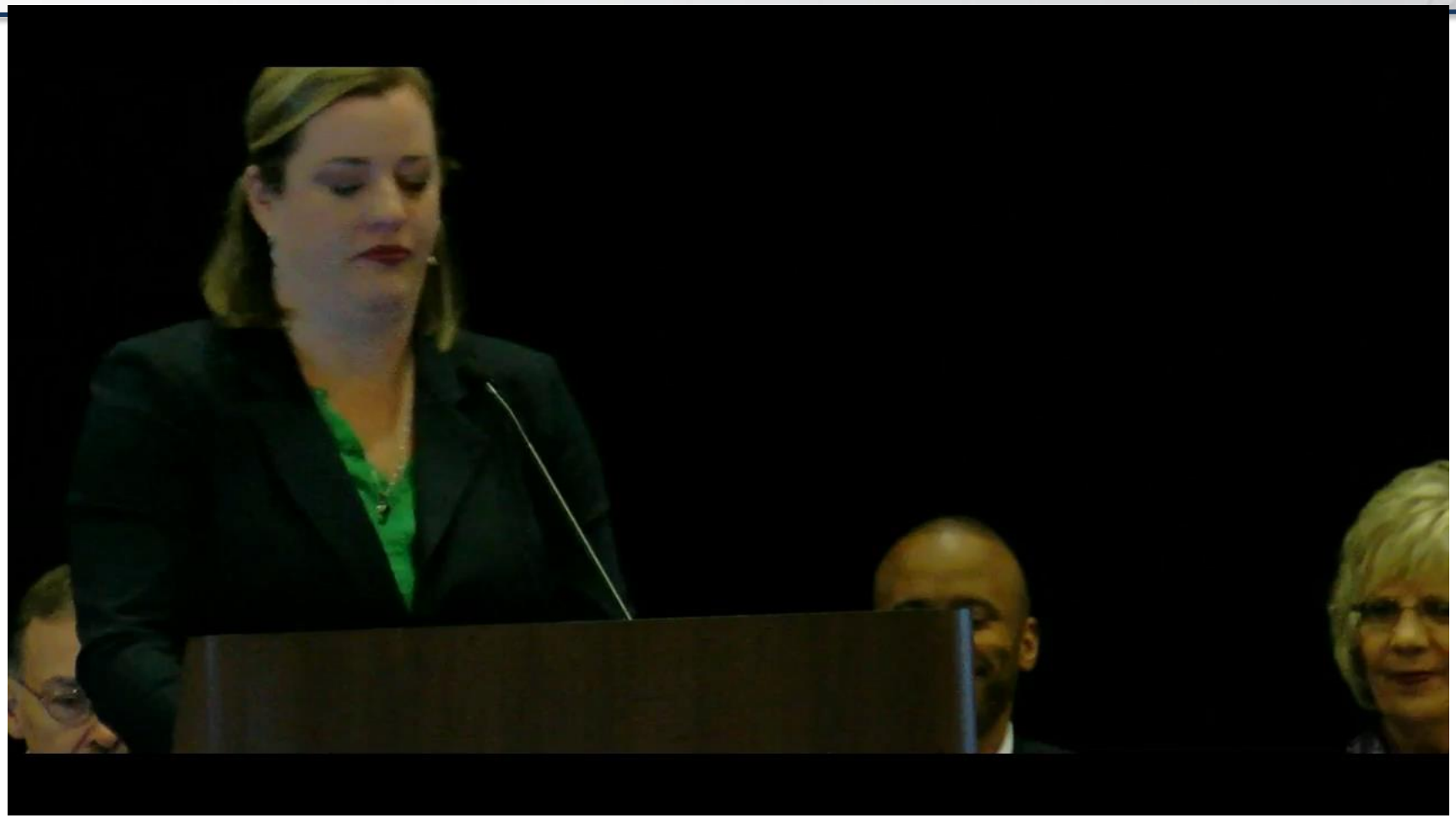
P.I.C.K. Teamed with US Government Department of Health and Human Services (HHS)

National Parent Education Campaign

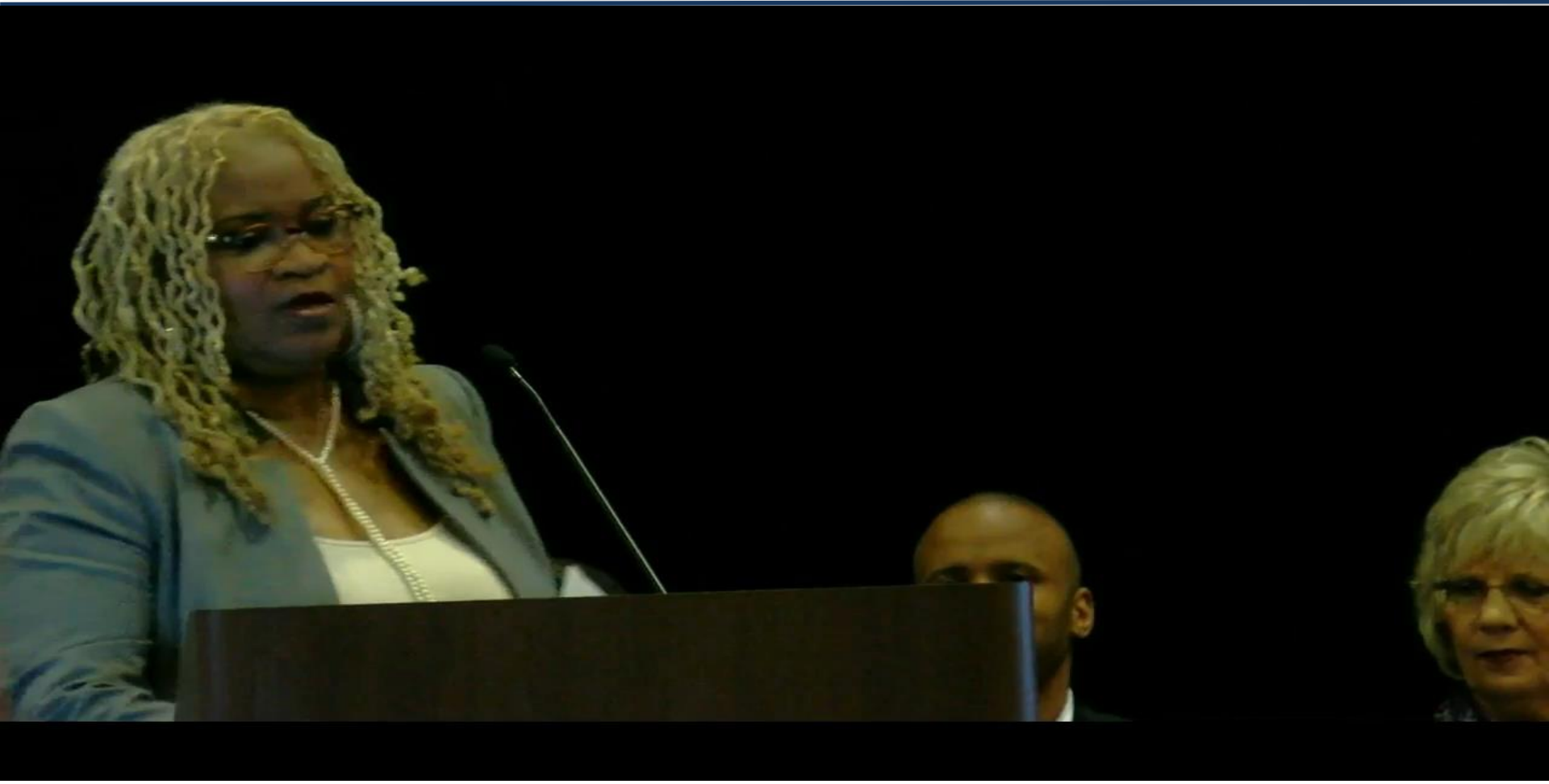
Health Care System Level
Case Study #2

Patients as Research Partners
SIDM's Patients Improving Research in Diagnosis (PAIRED)

Video-Susie



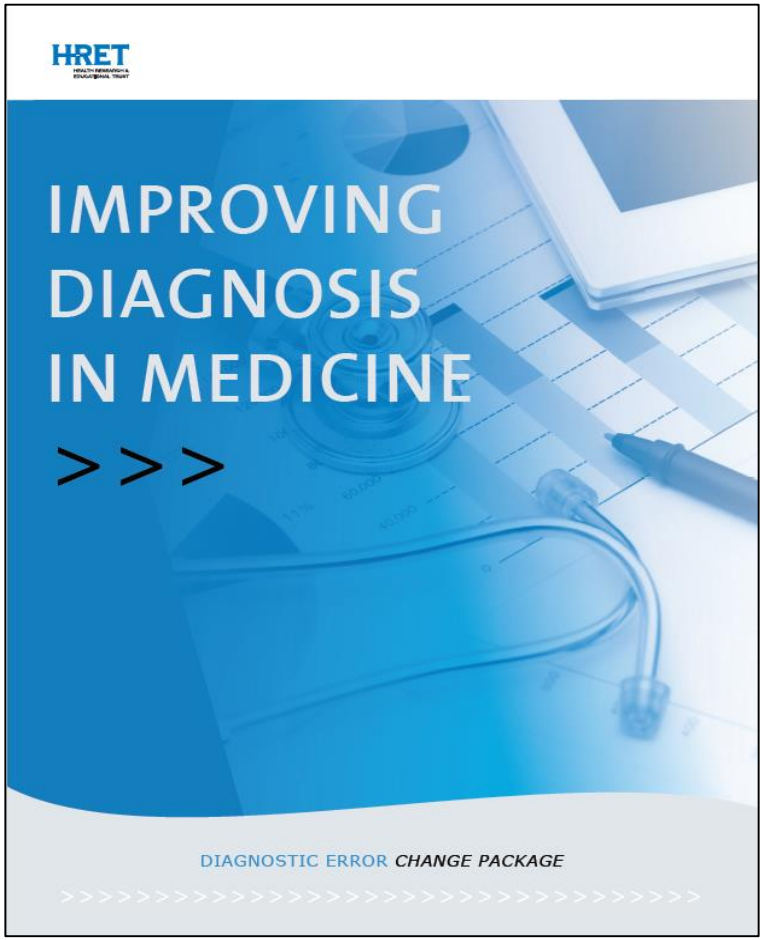
Video-Jeanette



Turning “What Ifs” into a Disparities Research Project

Health Care Organization Level

Health Research & Educational Trust (HRET) Change Package to Improve Diagnosis in Medicine

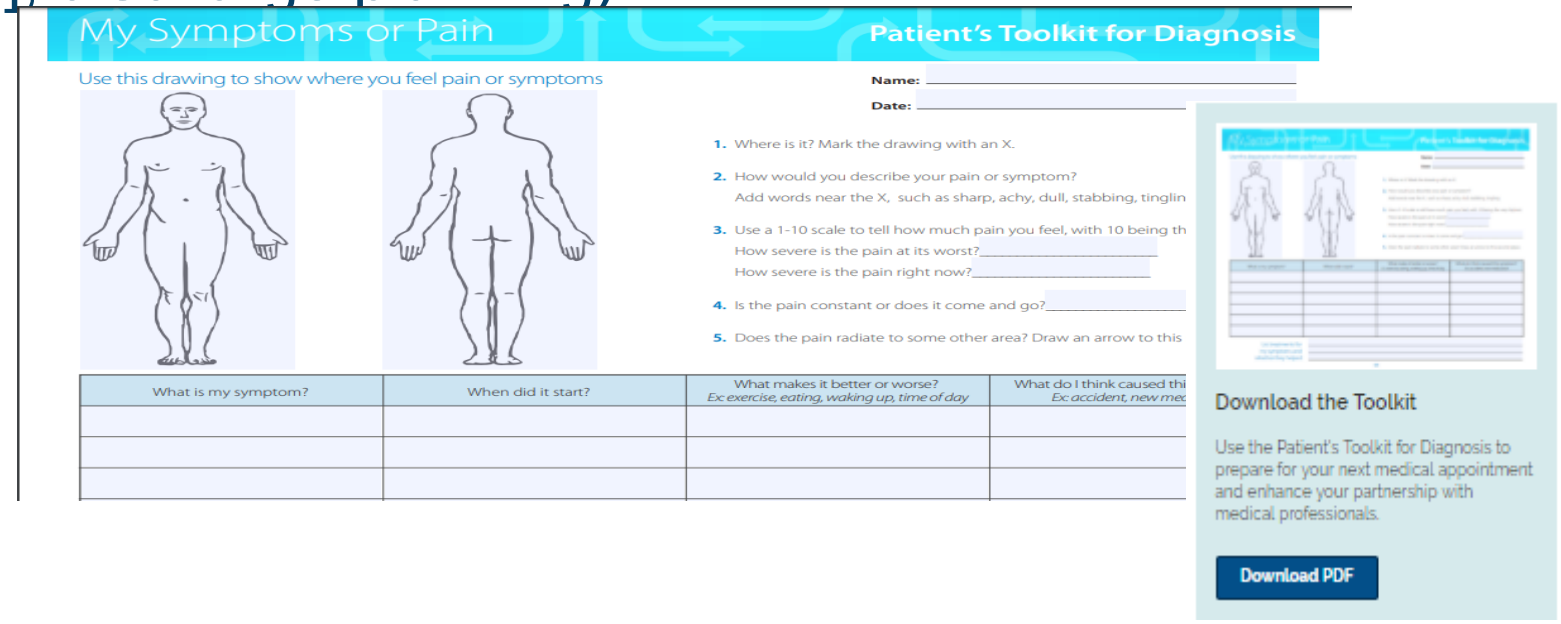


Patient and Family Engagement Change Ideas

http://www.hret-hiin.org/topics/diagnostic_error.shtml

Provide Tools for Patients to Participate in the Diagnostic Process

Create opportunities for patients and family members to use tools and learn about and participate in the diagnostic process **(SIDM Tool Kit,** preadmission checklist, shared decision making, teach back, patient activation strategies [PAM], discharge planning)



Utilize Empathetic Listening Tools

Teach empathy to members of the diagnostic team using an established or locally developed curriculum.
Teach and monitor active listening to members of the diagnostic team

AMA | STEPSforward

Listening with Empathy

Save time, communicate more effectively and improve patient and provider satisfaction

Provide Patient Portals and Access to Information

Provide patient and family member access to their electronic health records (EHRs), including clinical notes and test results, to facilitate patient review of health records for accuracy

Patients Participate on Governance, PFACs and Safety Committees

Provide orientation/training regarding diagnostic safety and quality to support patient and family participation in governance (PFACs, Practice Improvement Teams, Board Representatives, Research Teams, Policy, etc.)

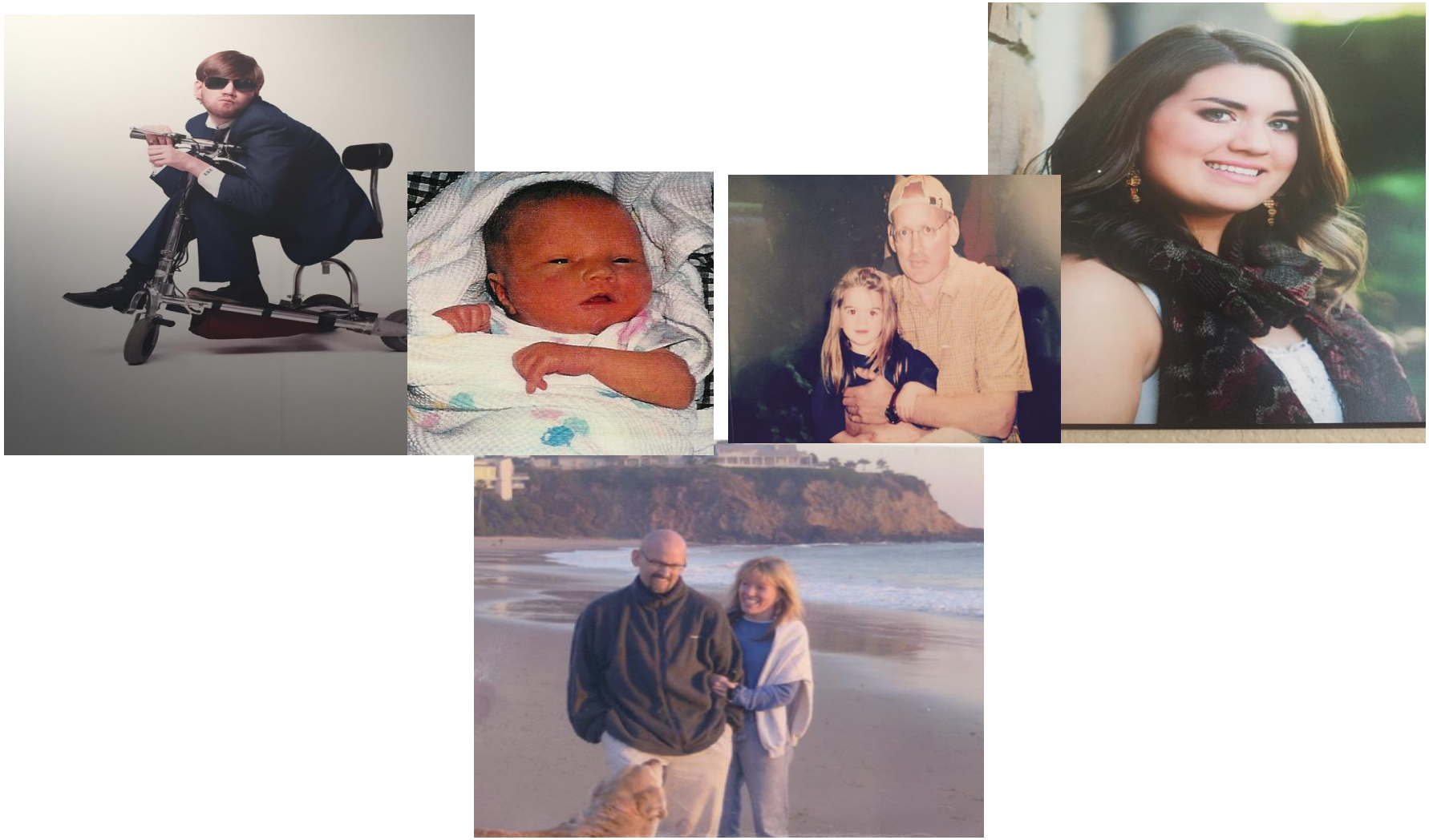
Role of Clinicians in Improving Diagnosis

- Invite patients to participate in the diagnostic process
- Help patients and families have full access to as much information as they want (practice guidelines, websites, unfettered access to the medical records and real time test results)
- Be honest about risk
- Instruct patients how to identify and report concerning symptoms
- Talk about uncertainty – Its OK

Role of Clinicians in Improving Diagnosis

- Discuss diagnostic options - the benefits and risks
- Explain diagnosis in understandable language and confirm patient's understanding of their diagnosis and actions to take
- Persist when diagnosis is difficult – maintain curiosity
- Resist biases – it harms
- Be humble
- Learn from patients
- Encourage patients to seek a second opinion
- Listen, listen, listen – only patients know what "normal" is for them and are the experts in their own bodies

Why Patient Engagement is Important in Preventing Diagnostic Errors



SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

What if: