**An Abbreviated List of Experts and Subjects**

In addition to the list below of people I have already interviewed, there are more families vying to tell their stories and more experts who are lined up to join their colleagues.

**Physicians & Researchers:**

- Mark Graber, MD, is the face of the movement to address diagnostic errors in medicine worldwide. In 2008 he convened and chaired the first Diagnostic Error in Medicine conference. In 2011 he founded the new Society to Improve Diagnosis in Medicine and serves as President of SIDM. Dr. Graber is a Senior Fellow at RTI International and Professor Emeritus of Medicine at the State University of New York at Stony Brook. He has an extensive background in biomedical and health services research, with over 70 peer-reviewed publications. He is a national leader in the field of patient safety and originated Patient Safety Awareness Week in 2002, an event now recognized internationally. We serve together on an advisory panel I am chairing for a post-doctoral study to create a taxonomy that can translate how patients speak about misdiagnosis into terminology researchers and physicians can use for research purposes. He co-authored "Diagnosis: Interpreting the Shadows" with three of the other experts on my list. It's the first medical textbook on diagnosis and will be published in June 2017.
- Hardeep Singh, MD, MPH, is widely considered the foremost researcher of diagnostic error in the United States. He is currently Chief of the Health Policy, Quality & Informatics Program at the Center for Innovations in Quality, Effectiveness and Safety at the Michael E. DeBakey VA Medical Center in Houston. He is also an Associate

Professor in the Department of Medicine, Section of Health Services Research at Baylor College of Medicine. Dr. Singh has won dozens of awards for his contributions to the effort to identify and improve diagnostics. He has authored and co-authored over 120 clinical studies on the topic. The seminal 473-page 2015 report by the National Academies of Sciences, Engineering and Medicine entitled "Improving Diagnosis in Healthcare" refers to Dr. Singh's research and conclusions over one hundred times and bases its most important conclusions on his research. I first interviewed Dr. Singh in September 2015 and we continue to speak periodically for this book and other research needs. He co-authored "Diagnosis: Interpreting the Shadows" with three of the other experts on my list. It's the first medical textbook on diagnosis and will be published in June 2017.

- Prashant Mahajan, MD, MPH, MBA is a pediatric emergency services expert and the lead investigator of a major clinical study on diagnostic errors in pediatric emergency rooms at four different hospitals. I met him when he asked me to serve on the expert panel of that study as the chief patient and family advocate. Mahajan is a Professor of Emergency Medicine and Pediatrics and the Vice-Chair, Department of Emergency Medicine and the Section Chief of Children's Emergency Services at Michigan Medicine, University of Michigan. He is a founding member of the Pediatric Emergency Care Applied Research Network (PECARN).
- Karen S. Cosby, MD, FACEP is a senior Emergency Medicine Physician at Cook County Hospital and Associate Professor at Rush Medical School. She has chaired the Fellowship subcommittee of the Society to Improve Diagnosis in Medicine (SIDM) and the patient safety interest group for the Society for Academic Emergency Medicine

(SAEM) where she led efforts to produce a curriculum for patient safety. She was a co-investigator of an AHRQ grant on diagnosis error. She has edited three textbooks (including *Patient Safety in Emergency Medicine)*. I wanted to meet Cosby ever since I read her extremely comprehensive 2003 paper *A Framework for Classifying Factors That Contribute to Error in the Emergency Department.* It predated many of the studies by the other experts listed here and became the basis for a great deal of other research. Cosby co-authored "Diagnosis: Interpreting the Shadows" with three of the other experts on my list. It's the first medical textbook on diagnosis and will be published in June 2017.

- Geeta Singhal, MD, MEd, is a pediatric hospitalist with an educational focus. She currently serves as the Director of Faculty Development and as an associate professor for Baylor College of Medicine in Houston, and is a practicing hospitalist at Texas Children's Hospital. She has co-directed a national educator conference, was a planning committee member for a diagnostic errors conference and is currently serving on the PHM 2015 conference planning committee. Dr. Singhal has co-authored many studies into diagnostic errors, including the oft-quoted work "Errors of diagnosis in pediatric practice: a multisite survey" published in the medical journal *Pediatrics*. I first interviewed Dr. Singhal for my story in *The Atlantic Magazine* and continue to speak with her on a range of issues related to this book. She recently introduced me to two pediatric specialists at Texas Children's Hospital who are renowned for their diagnostic skills and knowledge. They have also been interviewed for this book:
    - Satid Thammasitboon, MD, who is a pediatric critical care specialist at Texas Children's Hospital, an associate professor at Baylor College of Medicine, and has co-authored several papers in the fields of diagnostic and critical thinking; and

  - Jan Drutz, MD, a professor of pediatrics at Baylor College of Medicine and a hospitalist at Texas Children's who is known for his ability to solve pediatric medical mysteries. Dr. Drutz has been the local Principal Investigator for clinical research projects over the past several years, as part of the Continuity Research NETwork (CORNET), a collaborative effort of the Academic Pediatric Association Continuity Specialty Interest Group.

- David L Meyers, MD, FACEP, speaks his mind regardless of the consequences. He is an emergency physician and former Chair of Emergency Medicine at Sinai Hospital in Baltimore. He currently serves on the Board of Directors of SIDM (Society to Improve Diagnostic Medicine). Meyers has also served as Chief of the Medical Practice Division at EmCare, Inc., a large national physician practice management company where he was responsible for the risk and claims management and professional liability insurance programs for more than 7,500 clinicians and 6 million annual Emergency Department visits. He led the development and implementation of a number of successful initiatives to reduce diagnostic errors in high risk, high frequency conditions. He is active in the American College of Emergency Physicians (ACEP), where he chaired the first Patient Safety Task Force and the Quality Improvement and Patient Safety (QIPS) Section where he continues as a member of the leadership group. At Dr. Meyers invitation, I participate in a listserv he moderates on medical diagnostic errors and how to improve them with dozens of doctors, researchers, and patient advocates. They have served as a Greek chorus for this book.
- Paul L. Epner MBA, MEd, is EVP of the Society to Improve Diagnostic Medicine (SIDM) and a leader in creating the Coalition to Improve Diagnosis (CID), an

organization of 31 prestigious medical and patient safety groups and two governmental agencies, including the CDC. Paul is a strategic planning consultant in healthcare with special expertise in the field of laboratory medicine. Previously he spent 31 years with the Diagnostics Division of Abbott Laboratories working in the U.S., Japan and China. His final position at Abbott was as Director of Healthcare Improvement Initiatives in which he focused on solving problems facing the clinical laboratory profession. Today, he continues to focus his efforts on redefining the role of clinical laboratorians to focus more directly on improved patient outcomes. This work has led him to the field of diagnostic errors. Paul currently serves as President of the Clinical Laboratory Management Association (CLMA) and as Chairman of the AHRQ-funded annual Diagnostic Error in Medicine (DEM) Conferences.

- Ross Koppel, PhD, FACMI, is one of the foremost experts of healthcare IT and of the interactions of people, computers and workplaces. He is an influential critic of the multiple shortcomings of the electronic medical records most medical practices and hospitals use (EMRs and MHRs) and one of my favorite curmudgeons. Koppel and I have spoken many times and I often get wonderfully acerbic emails from him sharing the latest scandal in HIT. His articles in JAMA, JAMIA, Annals, NEJM, Health Affairs, etc. are considered groundbreaking works in the field. Professor Koppel is on the faculty of the Sociology Department at the University of Pennsylvania and also of Penn's Medical School. At the Med School he is the Principal Investigator of the Study of Hospital Workplace Culture and Medication Error. Dr. Koppel is also the Internal Evaluator of Harvard Medical School's project to create a new HIT architecture. On top of that, Ross Koppel is a co-investigator of the National Science Foundation Project on Safe Cyber

Communication and Smart Alerts in Hospitals. He coauthored the AHRQ Guide to reducing unintended consequences of HIT and wrote *First Do Less Harm: Confronting the Inconvenient Problems of Patient Safety* (Cornell Univ. Press, 2012).

- Pat Croskerry, MD, PhD, is considered one of the leading experts on medical cognitive errors, diagnostic errors and patient safety in emergency medicine. Croskerry is Professor of Emergency Medicine and in Medical Education at Dalhousie University in Halifax, Nova Scotia, Canada. He has contributed and spoken to the annual conference of the Society for Improvement in Diagnosis since its inception. Croskerry has published over 80 journal articles and 30 book chapters in the areas of patient safety, clinical decision-making and medical education reform. In 2006 he was appointed to the Board of the Canadian Patient Safety Institute, and in the same year received the John Ruedy award for innovation in medical education from the Association of Faculties of Medicine of Canada. He is senior editor of Patient Safety in Emergency Medicine (2009). He was appointed Director of the new Critical Thinking Program at Dalhousie Medical School, and a Fellow of the Royal College of Physicians of Edinburgh in 2012. In 2014, he was appointed to the US Institute of Medicine Committee on Diagnostic Error in Medicine and participated in the 2015 landmark study into diagnostic errors in America. Croskerry co-authored "Diagnosis: Interpreting the Shadows" with three of the other experts on my list. It's the first medical textbook on diagnosis and will be published in June 2017.
- Andrew White, MD, is Dr. House if the fictional character was as much fun as he was outrageous. White runs the Pediatric Residency Program at St. Louis Children's Hospital and, until it closed for lack of funds, co-directed SLCH's famed Diagnostics Center, a mecca for families from all over the country seeking answers to their children's medical

mysteries. Recently named a Philip R. Dodge, MD, Scholar in Pediatrics, White wears many other official hats: he's an associate professor of pediatrics at Washington University School of Medicine, he heads the pediatric rheumatology division at the School of Medicine and Children's Hospital, and he co-directs the Hereditary Hemorrhagic Telangiectasia (HHT) Center of Excellence, one of a handful of centers nationwide that treat the almost universally undiagnosed genetic disease.

- John Hickner, MD, MSCI, has been practicing family medicine in academic settings for 34 years and sees patients of all ages. Currently, he is an educator and family medicine practitioner at The University of Illinois Hospital system in Chicago. Dr. Hickner is also the editor-in-chief of the medical journal *The Journal of Family Practice.*

**Patient Advocates:**

- Helen Haskell has dedicated her life to help other parents avoid the fate of her child. Haskell is President of Mothers Against Medical Error, serves on the Board of Directors of the National Patient Safety Foundation, named a World Health Organization champion, and serves on the boards of Consumers Advancing Patient Safety, the Institute for Healthcare Improvement, and the International Society of Rapid Response Systems. She is a recently retired member of the AHRQ National Advisory Council, and a member of the steering committee of CUE, the consumer arm of the US Cochrane Center. She is a winner of Consumer Reports' first national Excellence in Advocacy award and in 2009 was named by Modern Healthcare magazine as one of the "100 Most Powerful People in Healthcare". While her personal story is one of medical error, not diagnostic error, the death of her 15-year-old son, Lewis Blackman, in a hospital for a routine surgery has

propelled her to work in all areas of patient safety. Helen is a treasure trove of helpful medical advice for parents.

- Sue Sheridan introduces herself as the mother of two children. While that's true, Sue is also a patient safety superwoman and she was interviewed for this book wearing both hats. (See sample chapter, The Sheridan Family). She is currently Director of Patient Engagement for the Patient-Centered Outcomes Research Institute (PCORI) and a member of the Board of Directors of the Society to Improve Diagnostic Medicine (SIDM). Previously, she was the external lead of the Patients for Patient Safety program at the World Health Organization (WHO), where she helped develop a global network of patients who built strategic plans for patient engagement for various WHO initiatives. Sue cofounded and is past president of Parents of Infants and Children with Kernicterus (brain damage from jaundice), who engaged with the healthcare system to implement a new standard of care in jaundice management. She is also a co-founder of Consumers Advancing Patient Safety, which helps organizations engage patients as partners in developing patient-safety solutions.
- Jason Maude's 3-year-old daughter nearly died when her pediatrician and the local hospital in Great Britain diagnosed her with Chicken Pox. What she had was Necrotizing Fasciitis and Toxic Shock Syndrome. Rather than suing the hospital, he worked with the doctor who saved her to create Isabel, a diagnostic software widely used by hospitals and physicians in Great Britain and the United States and available online to patients. It's part of the American Medical Association's physician portal. The twin stories of Isabel, the girl and the software, are compelling and motivating.

- Dan Berg is the father of Julia who died at 15 after gallbladder surgery due to multiple diagnostic errors and lab results that the attending doctors deemed "weird". Berg used the lawsuit proceeds to establish two annual lectures on patient safety and communication at the University of Minnesota Medical School Department of Pediatrics.
- Peggy Zuckerman turned her own multiply misdiagnosed stage IV kidney cancer and near-death into a career as a certified Patient Advocate speaking for patients of all ages and all medical conditions. Her blog is primarily focused on kidney cancer information for patients and caretakers, and she serves as a patient advocate for the online community SmartPatients.com, However, Zuckerman has spoken often and compellingly about diagnostic errors of all kinds. She serves on the board of SIDM (Society to Improve Diagnostic Medicine), co-authored their "Patient ToolKit," and has served as a spokesperson for them and the Society for Participatory Medicine, including interviews by major media outlets[1]. Her articles have appeared in the National Journal of Patient Safety. She is an outside consultant for Prometheus Labs, makers of the medication that cured her. Zuckerman serves on an advisory panel I am chairing for a post-doctoral study on translating how patients speak about misdiagnosis into terminology researchers and physicians can use.
- Maxine Eichner is an attorney and an expert on medical child abuse. She movingly wrote about both in her 2015 *New York Times* article "The New Child Abuse Panic." Eichner is a strong voice warning parents both about how to advocate for your child's health without losing him to a legal system that commonly sides with the medical establishment.

[1] Peggy Zuckerman's interview on NBC Nightly News https://youtu.be/Wh7llHd3SdI

**Parents/Patients:**

- Andrew S., father of a cancer patient who experienced debilitating head pain while in the midst of chemo treatments, with symptoms worse than the chemo side effects. The cause went undiagnosed and misdiagnosed for almost a year. The child - with help from his parents - started a non-profit for pediatric cancer survivors.
- Anna S., mother of a child with terrible stomach pains at 12-13. Nothing worked. One day, when they were having a MRI of her hip, the radiologist noticed something by accident. Turned out to be burst cysts in her ovaries.
- Jennifer L. is the mother of two sons. Her eldest had a simple fall in 6th grade, but his subsequent mood swings, sudden fever spikes, memory loss, confusion, and inability to stay awake would keep one of Boston's top neuro teams on the trail for over a year.
- Nancy D. may be a developmental psychologist but her education was of little help when her son was diagnosed with a common stomach bug in 6th grade. His daily nausea, migraines, vertigo, and brain fog puzzled all of the pediatricians, neurologists and pain specialists he saw for years.
- Cindy and Alex H., mother and daughter, tell two sides of a family's search for answers to the source of Alex's debilitating migraines, constant thirst, and motion sickness, which would afflict her school years from 5th grade through college graduation.
- Marla F. is a philanthropist focused on preventing racial, ethnic, and religious intolerance. She and her daughter are still in the midst of a diagnostic quest that has led them to seek help from dozens of doctors in six states. Each time they thought they had an answer, N's symptoms would evolve. In one example that demonstrates the lengths that they have had to traverse, a surgeon reconstructed N's whole skull to realign it with

her brain and eyes. Tiny little strings connecting the various bones in the skull remained outside her skin. As N looked at an eye chart, the surgeon micro-manipulated each of the strings until N exclaimed that the letters were straight and singular, instead of crooked and doubled.

- "We're bleeders," one of the family members explained to the hematologist. So much so that the Thanksgiving table settings for 40 routinely included a dozen boxes of tissues. They thought that nosebleeds ran in the family. Until one of the children died, bleeding out in an MRI machine in the local emergency room, the family didn't know about HHT, a genetic blood disorder that is considered the most underdiagnosed disease.