

Helene M. Epstein | Writer. Author. Advocate.



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I've grown accustomed to being the only person in the room without an MD after my name. Since 1999, I've served on committees, panels, and boards of directors for medical research projects, healthcare organizations, public schools, and grant-givers. I first became an advocate for families dealing with crisis when my son's complex 15-year diagnostic journey began in 1994. I've been a published writer for over 25 years, known for turning complex issues into accessible information so readers can apply the information to their own lives. I've done so for topics ranging from healthcare to policy to parenting issues, and many more.

Healthcare-Related Experience

Freelance Writer | 1990 - Present

I created the column [Dx IQ](#) for the Society to Improve Diagnosis in Medicine's patient engagement efforts. I'm in research mode for a narrative nonfiction book on pediatric diagnostic error. Hired pen for consumer magazines, business, online and literary publications under the bylines Helene M. Epstein, H.M. Epstein and Helene Kalmanson (maiden name). Articles cover a wide range of topics including healthcare, parenting, policy, architecture, and religion. I'm a member of the Association of Healthcare Journalists (AHCJ), the American Society of Journalists and Authors (ASJA), and literary society Pen Parentis.

Member of the Board of Directors at Brightpoint Care | June 2015 - Present

Brightpoint Care (formerly Brightpoint Health) is a leading nonprofit provider of high-quality medical and mental health care as well as social support services to people, families and communities challenged by health disparities. I serve on their board of directors and — until January 1999 — on the Quality Improvement sub-committee working closely with the staff on policies and procedures.

Expert Panel Member of two AHRQ-funded research projects at Michigan Medicine | January 2016 - Present

I serve as a consultant, in my role as a parent and patient advocate, for two multidisciplinary expert panels guiding AHRQ-funded research projects:

- "Missed Opportunities for Improving Diagnosis in Pediatric Emergency Care" [MOIDs]. The goal of the MOIDs multi-year research project is to better understand missed diagnostic opportunities in pediatric EDs so that we can develop strategies to reduce them. Based on the first year's work, I co-authored "An Operational Framework to Study Diagnostic Errors in Emergency Departments: Findings from a Consensus Panel." This paper is soon-to-be published in the peer-reviewed Journal of Patient Safety.
- Beginning soon: "Improving Diagnosis in Emergency and Acute Care: A Learning Laboratory" (IDEA-LL). The goal is to develop and use innovative systems engineering-based approaches for better measurement and reduction of diagnostic error in the Emergency Department.

Patient Engagement Committee at the Society to Improve Diagnosis in Medicine (SIDM) | July 2017 – Present

All of the members of SIDM's Patient Engagement Committee (PEC) are patient advocates focused on educating, communicating, and engaging patients. Our goal is to develop a skilled, diverse national and international community of patient thought leaders knowledgeable about diagnostic quality and safety.



Chair – Advisory Board for an AHRQ-funded Research Scientist Development Award at Baylor College of Medicine | September 2018 – Present

I serve as the chairman, and as a consultant in my role as a patient advocate, for a multidisciplinary advisory board guiding an AHRQ-funded project entitled “Engaging Patients in Diagnostic Error Reporting.” The goal is to develop methods to help collect rich, illustrative diagnostic error experiences from patients and help create actionable data for healthcare systems. The overall objective of this career development award is to couple participatory research methodology with a consumer-focused informatics approach to develop and test an electronic, patient-centered, diagnostic error-reporting system.

Member of a Joint Initiative to Address Diagnostic Error at Institute for Healthcare Improvement/National Patient Safety Foundation/Society to Improve Diagnosis in Medicine | 2017

The project developed a model to guide quality improvement and potential measures for evaluating these activities, defined interventions and a change package intended to reduce harm associated with the diagnostic process. I served as the sole patient advisor to six sponsored trials of promising interventions in partnership with collaborating healthcare institutions, including Children’s Hospital of Philadelphia, Northwell, Yale, UCSF, and Nationwide Children’s Hospital.

Other Experience

Youth Development Allocations Panelist for the United Way of Greater St. Louis, MO | 2014 - 2015

Each year, we visited half of the local youth development organizations funded by the United Way to evaluate their programs, leadership, and future viability. Convened with the other panelists and staff members to participate in the funding decision-making process based on the monies raised and how well the organizations met the UW criteria and metrics.

Regional Arts Commissioner of St. Louis, MO | January 2014 – June 2015

Our goal was to promote, encourage and foster the arts and cultural institutions in St. Louis City and County, as well as to create an environment that nurtures artists and cultural organizations. The Regional Arts Commission of St. Louis (RAC) is a quasi-government agency that reallocates hotel tax funds to fund the arts. RAC is governed by a 15-member board of Commissioners appointed by the Mayor of St. Louis and the St. Louis County Executive.

Co-chair/Committee Member for the Briarcliff Manor Union Free School District, NY | September 1999 – June 2010

I served on various committees for the school, the school board and the PTA, including Publicity Chair for the School Referendum, Public Relations Chair for the PTA, Chair of the Elementary Compact Committee which introduced an arts in education model, and Member of the Principal Search Committees for both the Elementary and Middle Schools. I also served on two, year-long K-12 district-wide committees, one dedicated to reducing unnecessary stress and the other on addressing students’ special needs. I worked closely with the Superintendent of the district and the special education departments of all three schools.

Education

New York University

Bachelor of Science (B.S.) Cum Laude, University Honors Scholar.