



The Herman & Walter Samuelson
**CHILDREN'S
HOSPITAL AT SINAI**
A LIFE BRIDGE HEALTH CENTER

Division of Pediatric Hematology/Oncology
The Children's Hospital at Sinai
2401 West Belvedere Avenue
Baltimore, Maryland 21215-5271
Tel 410 601 5864

AZIZA SHAD, MD
Chairman, Department of Pediatrics
JASON M. FIXLER, MD
YORAM UNGURU, MD, MS, MA
JENNIE HART, MD
YEVGENIYA (JACKIE) BAMME, MD
STACEY UDDEME, BSN, RN, CPN
Nurse Coordinator
ALLISON SCHAULE, BSN, RN
Unit Coordinator
CHARMAINE GRANDISON-JOHN, BSN, RN
Nurse Navigator
SHANNON ROSENBAUER, LCSW-C
Social Worker

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Written Testimony in Support of HB 1323

Treatment Decisions for Unrepresented Hospital Patients

Submitted by Dr. Yoram Unguru, Attending Physician and Ethics Committee Chairman, Sinai Hospital of Baltimore, and Associate Professor, Johns Hopkins University School of Medicine; Core Faculty, Johns Hopkins Berman Institute of Bioethics

Madams Chair and Vice Chair, and Members of the Committee, thank you for the opportunity to submit written testimony with my strongest support for HB 1323.

My name is Yoram Unguru. I am pediatric hematologist/oncologist at Sinai Hospital of Baltimore where I also serve as Chair of the Hospital Ethics Committee and Chair of the Medical Executive Committee. I am also Core Faculty member, Johns Hopkins Berman Institute of Bioethics and Associate Professor, Johns Hopkins School of Medicine.

Unrepresented patients - patients who lack decision-making capacity who do not have a surrogate decision-maker – are cared for every day in Maryland hospitals. Unrepresented patients lack a voice and are unable to express their preferences for care. As a result, their care often deviates from accepted and appropriate standards and often, they suffer from over-treatment, under-treatment, or delayed treatment. Additionally, unrepresented patients tend to remain hospitalized much longer than other patients (recent studies suggest twice as long) placing them at-risk for a range of hospital-acquired conditions, including, but not limited to, infections and medical errors. As unrepresented patient's wishes for care are unknown, clinicians who care for them struggle to “do right” by these patients. Absent threat of life or loss of limb, and without the patient's or their surrogate's consent, legally, clinicians are constrained from administering many aspects of routine care. Furthermore, while awaiting the lengthy and cumbersome appointment of a guardian, when unrepresented patients linger and languish in the hospital, hospital costs unnecessarily increase while scarce hospital beds remain unavailable for other deserving patients.

Ms. D was an unrepresented patient at my hospital whose care encapsulated many of these issues. I met Ms. D in my role as an ethics consultant. In her mid-60s, Ms. D had a sister and an aunt, neither of whom knew her well or were willing to serve as her representative or surrogate, instead deferring to the clinical team. Ms. D had numerous acute and chronic medical conditions, including advanced emphysema, respiratory failure, and recurrent infections. For the greater part of the past year, Ms. D had been repeatedly hospitalized with lengthy admissions lasting up to several months at a time. During the most recent hospitalization, Ms. D contracted numerous infections, which were resistant to all known treatments such that there was no effective available treatment. Ms. D's medical team deemed ongoing treatments for the resistant infections as medically ineffective and unlikely to result in meaningful improvement in her condition.

Seven months earlier, when she still had the ability to voice her preferences, based upon her medical condition at the time and before she had developed multi-drug resistant infections, Ms. D had requested “*all interventions & resuscitative efforts.*”

Subsequently, Ms. D's clinical status had dramatically changed and she no longer had decision-making capacity. Unfortunately, the medical team was unable to engage Ms. D in goals of care discussions. Without knowledge of her preferences, values or wishes, there was no way to know whether Ms. D would (still) want all interventions and resuscitative efforts pursued in her current and very different condition.

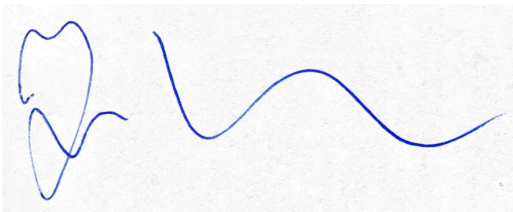
In the absence of clear guidance, clinicians vary widely in how they make specific decisions for patients. Data suggests that clinicians' treatment decisions may be influenced by medically irrelevant features such as race, gender identity, ethnicity, religion, socioeconomic status and clinicians' implicit biases. Appointing a guardian takes time, time that unrepresented patients and clinicians often do not have. Thus, patients, clinicians, and hospitals require and deserve a different approach such as that proposed by **HB1323**. HB1323 provides a nuanced, defensible, and transparent solution based upon a fair and practical process for treatment decisions for unrepresented patients.

The status quo for unrepresented patients is woeful and inadequate. When Hospitals and clinicians await guardianship and are left to decide on their own as to a patient's care, treatment may occur without the patient's consent and may be against their wishes, violating their dignity.

Unrepresented patients are among the most vulnerable Marylanders. They absolutely deserve better care and protections. HB1323 represents a patient-centered and accountable process which provides a much-needed improvement over the current practice.

Thank you for your consideration and support of HB1323.

Respectfully,

A handwritten signature in blue ink, consisting of a stylized first name followed by a long, wavy line representing the last name.

Yoram Unguru, MD, MS, MA, HEC-C
Attending Physician
Division of Pediatric Hematology/Oncology
The Herman & Walter Samuelson Children's Hospital at Sinai
Chairman, Sinai Hospital Ethics Committee
Core Faculty, Johns Hopkins Berman Institute of Bioethics
Associate Professor, Johns Hopkins School of Medicine