**A Proposal for Legislative Action Concerning Medical Decisions for Unrepresented Patients\***

*A young woman sustained permanent brain damage from the rupture of a brain aneurysm. Her kidneys also failed and she required kidney dialysis three times a week. Her family refused responsibility and would not authorize her treatment, due to legal concerns and post-stroke behavior that they could not control. She remained in an acute-care hospital for more than a year due to the inability to obtain a guardian because of the complexities of her medical, behavioral and social situation.*

*An elderly man was admitted for a bloodstream infection and found to have dementia and to require supervised treatment for tuberculosis. The patient’s family had not been in touch for several decades, and refused to participate in healthcare decisions due to his past history of abuse. The patient refused all evaluation or treatments, so he was kept in the acute setting to receive supervised TB treatment mandated by public health officials. He eventually developed hospital-related infections and died in the hospital, 3 months after admission, on the day his guardianship hearing was finally scheduled.*

***Unrepresented patient***: An adult patient who lacks decisional capacity to give informed consent for medical treatment, does not have an applicable advance directive, and for whom there is no legally authorized surrogate decision maker, family, or friend available, competent and willing to assist with medical decision-making. Also referred to as *unbefriended patient*, *adult orphan*, and *patient without proxy*.

**Scope of the Problem**

* Growing numbers of the elderly and other chronically ill adults suffer from dementia and have abandoned or been abandoned by family, outlived family and friends, or have lost contact with their community.
* Persons who are homeless or have intellectual/developmental disabilities may not have guardians, representation, or a stable community.
* Published studies show that 5% of the 500,000 patients who die each year in U.S. ICUs are unrepresented and incapacitated.
* In one study, 3-4% of nursing home residents were unrepresented and in another study more than 16% of patients admitted to intensive care units of hospitals were unrepresented. By 2030, it is estimated that more than 2 million adults over the age of 70 will have outlived all of their friends and family members.
* In an informal survey of 34 skilled nursing and assisted care facilities in CO, 28 facilities reported having at least one unrepresented resident and some reported 20% to 50% of residents as unrepresented. More than half of the facilities reported that some portion of those residents, as much as 20%, also lack decisional capacity. They reported guardianship requests taking anywhere from 1 to 12 months, with the average being 4-6 months.
* Inpatient hospitals report similar delays of at least 6-8 weeks, and often several months, to establish a court-appointed guardian.
* The Colorado Revised Statutes lack clarity about the process for medical decision making when patients lack capacity and are unrepresented, rendering these patients among the most vulnerable in our communities.
* Unrepresented patients often endure substantial delays in receiving medically beneficial elective treatments or discharge to a less restrictive and medically more appropriate environment. Providers may hesitate to initiate new treatments and may postpone surgeries or other more elective interventions until they become emergencies, increasing the risks of these interventions, prolonging suffering and pain, and compromising the quality of care. Prolonged institutionalization can jeopardize a person’s financial situation or long-term housing.
* Critical decisions regarding highly invasive end-of-life treatments are also delayed, often resulting in potentially avoidable suffering and an unnecessarily prolonged dying process. It has been estimated that patients without representation spend an average of 50% more time in intensive care units than those whose wishes are known.

**Request for Legislative Action**

**We are seeking legislation to create authority within the medical proxy statute for healthcare providers to act on behalf of unrepresented patients to make medical treatment and placement decisions during the period in which the patient is without capacity and formal guardianship is being sought.**

\*The **Colorado Collaborative for Unrepresented Patients** consists of representatives of the following institutions: Center for Bioethics and Humanities, University of Colorado Anschutz Medical Campus; Center for Ethics and Leadership in the Health Professions, Regis University; Children’s Hospital Colorado; Colorado Healthcare Ethics Forum; Denver Health and Hospital Authority; JFK Partners, University of Colorado School of Medicine; and University of Colorado Hospital Authority.