



Date: June 13, 2023

To: Members of the Uniform Law Commission

Re: Revision of the Uniform Determination of Death Act (RUDDA)

I am writing on behalf of the Board of Directors of the Healthcare Advocacy and Leadership Organization (HALO), “a voice for the medically vulnerable.” We are volunteer patient advocates who promote the well-being and rights of patients and their families. We strive to educate the public about a wide array of ethical issues they may face in various healthcare settings, including organ donation, procurement, and transplantation practices. In all circumstances, HALO promotes ethical, life-affirming medical care and treatment.

“Brain death” is a label we reject because it is a legal fiction. The Uniform Determination of Death Act was adopted to facilitate organ procurement for transplantation, not to ensure that people who are declared dead are certainly dead. Harvard ethicist Robert Truog, M.D., contends the “central justification equating brain death with biological death is now known to be false.”ⁱ

The Drafting Committee’s effort to revise the seriously flawed UDDA is a challenging task. HALO’s Board of Directors hopes you will consider our concerns moving forward. In the interest of brevity, this letter does not address all our concerns regarding the proposed revision of the UDDA (RUDDA). Our focus is on this draft language:

Section § 3 (a) An individual is dead if the individual has sustained:

Option 2

- (1) permanent cessation of circulatory and respiratory functions; or
- (2) permanent (A) coma, (B) cessation of spontaneous respiratory functions, and (C) loss of brainstem reflexes.

“Permanent” Is Not an Improvement Over “Irreversible”

Section § 3 (a) Option 2 is a subjective definition of death without a biological basis.

“Permanent” is not an improvement over the word “irreversible.” The word “permanent” applies when physicians do not intend to provide treatment which may reverse a patient’s condition. Therefore, a person who is biologically alive, but comatose, will be declared legally dead when physicians refuse to act to reverse his or her condition.

The proposed change is from UDDA (2) “irreversible cessation of all functions of the entire brain, including the brain stem” to “permanent coma, permanent cessation of spontaneous respiratory functions, and permanent loss of brainstem reflexes.” Both the UDDA and the RUDDA define as dead a person who has a beating heart, circulation, respiration (exchange of oxygen and carbon dioxide in lungs and tissues), functioning liver and kidneys, maintenance of body temperature, wound healing, and other signs of life. Both definitions require that we not believe our senses, that we deny what we can plainly see – a living person.

Death Ought Not to Be Declared Unless in Accord with Indisputable Signs

In 2008, the President’s Council on Bioethics affirmed the UDDA. The Council’s chairman, Edmond D. Pellegrino, M.D., wrote in his minority dissent, “The only indisputable signs of death are those we have known since antiquity, i.e., loss of sentience, heartbeat, and breathing; mottling and coldness of skin; muscular rigidity; and eventual putrefaction as the result of generalized autolysis of body cells.” HALO agrees with Dr. Pellegrino and like-minded professionals. Therefore, HALO hopes the ULC Drafting Committee will heed the recommendation of Dr. Paul A. Byrne, a board-certified pediatrician and neonatologist, Founder and President of the Life Guardian Foundation, to repeal the UDDA and replace it with this language:

“No one shall be declared dead unless respiratory and circulatory systems and the entire brain have been destroyed. Such destruction shall be in accord with universally accepted medical standards.”



In the unfortunate event the Uniform Law Commission retains the UDDA's current language or accepts the proposed revisions, HALO urges the Commission to adopt the proposed language allowing patients and their legal representatives to refuse any test used to determine "brain death" and to opt out of being declared "brain dead."

At the very least, people deserve to be told the truth and afforded the opportunity to give **informed** consent or refusal to organ donation. D. Alan Shewmon, M.D., says it best: "Just as cigarette ads are required to contain a footnote warning of health risks, ads promoting organ donation should contain a footnote along these lines: 'Warning: it remains controversial whether you will actually be dead at the time of the removal of your organs.'"ⁱⁱ

Sincerely,

Dennis Merritt

Dennis Merritt, President

Board of Directors, Healthcare Advocacy and Leadership Organization

ⁱ Truog RD, "The Uncertain Future of the Determination of Brain Death," *JAMA* online, February 07, 2023.

ⁱⁱ Shewmon DA, "Brain Death: Can It Be Resuscitated?" *The Hastings Center*, April 19, 2010.