

To: Chairman Samuel Thumma and All Members of the Determination of Death Act Committees & Style/Drafting Committees

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

I am the President of Life Guardian Foundation (LGF) and writing on behalf of the Board of Directors. We are volunteer patient advocates who protect and preserve their life until death, their well-being, and rights of patients and 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, LGF promotes ethical, life-affirming medical treatment and care.

"Brain death" is a label we reject because it is a legal fiction. The Uniform Determination of Death Act (UDDA) was adopted primarily to facilitate organ procurement for transplantation.

The Drafting Committee's effort to revise the seriously flawed UDDA has drawn attention. LGF's Board of Directors hopes you will consider our concerns moving forward. This letter does not address all our concerns regarding the UDDA and the proposed RUDDA. Our focus is on the draft language of Section 3, Option 2, in preparation for June 9, 2023, informal session:

"Section 3. Determination of Death

(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." The word "permanent" applies when physicians do not intend to provide treatment that may reverse a patient's condition. Therefore, a person who is biologically alive, but unresponsive, will be declared legally dead when physicians refuse to act to reverse his or her condition.

The proposed change is from "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." The whole brain standard alone is not death, and neither are: "permanent (A) coma, (B) cessation of spontaneous respiratory functions, and (C) 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. Edmond D. Pellegrino, M.D., Chairman of the President's Council on Bioethics wrote, "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." LGF agrees with Dr. Pellegrino's statement and other like-minded professionals.

LGF hopes that the ULC Committee will heed my recommendation as a board-certified pediatrician and neonatologist, Founder and President of the Life Guardian Foundation, who has studied and followed "brain death" for decades, 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, LGF 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 any time in the process, not just prior to initiation of the "brain death" exam, any testing, determination, and declaration protocols.

At the very least, people deserve to be told the truth including full and complete information that will afford the opportunity to give **informed** consent or refusal to both "brain death" exams, protocols, including but not limited to the apnea test procedure, determinations, declaration and any organ donation.

Sincerely,

Paul A. Byrne, M.D.

President, Life Guardian Foundation,

Board of Directors, Life Guardian Foundation