



June 8, 2023

Transmitted Via Email
Honorable Sam Thumma
Professor Nita Farahany, Esq.
National Council of Uniform Law Commissioners

Dear Commissioners:

Heidi Klessig, MD, and I, Christopher W. Bogosh, RN-BC, B.Th., represent Respect for Human Life, a patient advocacy organization. We are writing to take strong exception to the proposed revisions to the UDDA, which will further erode the civil rights of vulnerable patients with brain injury.

Specifically, changing the requirement from “irreversible” to “permanent” will allow still-living people whose prognosis is death to be declared legally dead, which could be a grave injustice to registered organ donors who never received informed consent about their state of being at the time of the harvesting of their organs (i.e., their heart is still beating, their lungs are aerating, often parts of their brain are still working, and many have been misdiagnosed).

Further, gerrymandering the critical parts of the central nervous system down to just the brainstem reflexes, which can be tested at the bedside, is arbitrary and perverse. While we have all the technology of the 21st century at our disposal, just using the tests available in the 1800s to make a life-or-death decision is weighing the scales against these helpless people.

In addition, removing the right to informed consent regarding the apnea test, or even allowing the apnea test to proceed above the consent of the family or legal surrogate, is a step back to the worst examples of medical paternalism. Moreover, the apnea test does nothing for the critically injured patient and only serves unspecified “others” needing organs or to free up ICU beds—both serve the financial interests of medical institutions and not the patient. The apnea test decreases cerebral blood flow and can cause further brain injury in a traumatized brain. Thus, removing this right to informed consent will violate the ethical principles of autonomy, beneficence, and non-maleficence.

Everyone is a sovereign stakeholder over his right to life. The United States Constitution protects this God-given right. The interests of “transplant stakeholders” do not supersede the patient’s

right to self-determination, especially without providing informed consent. Organ procurement organizations' deceptive propaganda campaign at DMV sites nationwide is a travesty of justice since these organizations do not disclose all the facts. Notably, organ donors are pronounced dead based on the legal fiction of the flawed Uniform Determination of Death Act (UDDA) and do not meet the Dead Donor Rule (DDR). Registered organ donors give the gift of their own lives to benefit several strangers, while "transplant stakeholders" rake in billions from Medicare and Medicaid. The interests of others who may want our organs do not supersede our right under the law to informed consent and *then to* self-determination after all the facts of potential or actual medical intervention are disclosed.

It is paramount, to quote D. Alan Shewmon, MD, and 107 experts in medicine, bioethics, philosophy, and law: "People have a right not to have a concept of death that experts vigorously debate imposed upon them against their judgment and conscience; any revision of the UDDA should therefore contain an opt-out clause for those who accept only a circulatory-respiratory criterion."

We respectfully request that the revisions to the UDDA be dismissed. If the proposed revisions proceed, we insist that an opt-out clause be included to protect the patient's right to informed consent and self-determination.

Sincerely,



Christopher W. Bogosh, RN-BC, B.Th.