



June 8, 2023

Via Email

Honorable Sam Thumma

Professor Nita Farahany, Esq.

National Council of Uninform Law Commissioners

On behalf of Midwest Transplant Network (MTN), the federally designated Organ Procurement Organizations (OPO) serving 5.6 million individuals in Kansas and western Missouri, we write to express our concern regarding sections of the Draft Revised Uniform Determination of Death Act (UDDA) submitted for initial review on April 20, 2023. MTN has the CMS distinction as a Tier 1A, high-performing OPO. We are committed to saving lives by facilitating the organ donation process and are concerned that the additional optional language proposed by the drafting committee related to notification, time to gather, and accommodation will have a chilling effect on donation and transplantation within MTN's Donor Service Area (DSA) if enacted by state legislatures. Therefore, we encourage Commissioners to:

1. remove proposed section of the revised UDDA mandating notice of the examination;
2. strengthen and maintain the UDDA's position that consent is not required for the examination; and
3. ensure the statute does not provide the ability to block the death determination exam or death declaration.

Because OPOs, like MTN, are mandated by state and federal law to facilitate the anatomical donation process, we feel that we have broad-based experience regarding how the legal definition of death is operationalized into clinical practice by medical professionals. Additionally, MTN staff members regularly approach the families of patients who are suspected or confirmed braindead, or whose death is imminent due to a planned withdrawal of treatment, to educate them on organ and tissue donation and offer families the opportunity to make a life-saving gift. Further, MTN staff members witness the unique circumstances that health care professionals must navigate everyday with every patient and their families as they contemplate end of life decisions, which is why we are opposed to the inclusion of unprecedented "restrictions" and "conditions" surrounding diagnostic determinations and clinical decision-making by medical professionals in the Committee's most recent draft.

The proposed optional sections, if adopted, would be inconsistent with how the law defers to the practice of medicine, and we assert that the newly added or contemplated sections of the UDDA requiring notice and consent for the examination and the ability to block the death determination or declaration would inappropriately infringe on the practice of medicine as well as the statutory right to be an organ donor and would adversely impact the care of patients and their families.

The need to determine neurologic status is a baseline determination of facts, and the exam itself presents no risk to the patient. To date, there are only two states that allow some restriction on declaration of death determined neurologically and that restriction must be based on the *patient's* and not the family's belief system. However, the Committee's proposed optional sections will create delay

in performing a neurologic exam or result in a failure to ascertain the neurologic status of a patient, which creates increased uncertainty at the end-of-life and threatens a *donor's* desire to make an altruistic, life-saving gift.

Overarchingly, we are concerned that the proposed optional language is not designed to solve an existing problem in the end-of-life or donation context. At MTN we have received no complaints or concerns from our hospital partners regarding current neurologic testing or declaration of death processes. In fact, we have observed that hospitals have finely tuned and detailed processes and policies that govern end-of-life care and medical professionals have been utilizing their medical judgment to navigate these processes for decades. Further, we have not observed any public outcry or complaints from families regarding who is permitted to gather at the bedside (outside of COVID-19 restrictions) and MTN's Family Support Coordinators routinely work with families and hospital staff to ensure each relative has ample opportunity to visit their loved one throughout the death determination and declaration process.

We encourage the Committee to contact hospital associations, the American Medical Association, hospice workers, social workers, chaplains and other groups or professionals involved in end-of-life care to vet the proposed optional language and provide input regarding whether the language addresses any existing issues, or rather, muddles an already complex process. Moreover, we caution the Committee not to advance a statute that cannot be enacted in *every* state to avoid the confusion that will occur if an individual who is declared dead in one state is not considered legally dead in another state. Any inconsistency related to whether an individual is legally dead will complicate donation and transplantation in the United States, which relies on interstate cooperation.


Finally, MTN recognizes the importance of the Committee's work on the UDDA and appreciates the Committee's goal to achieve legal clarity, certainty and public trust; however, this goal can only be achieved by maintaining the equal standing of neurologic and circulatory diagnosed deaths, with regard to notice, consent for testing and declaration.

Thank you for the countless volunteer hours you have spent working on this important topic. We appreciate your time and attention to our concerns and look forward to working with the Commission as you continue your work.

Sincerely,

A handwritten signature in blue ink, appearing to read "Jan Finn".

Jan Finn, President & Chief Executive Officer

A handwritten signature in black ink, appearing to read "Salama Gallimore".

Salama Gallimore, General Counsel and Advisor on Governmental Affairs