



Attention: Members of the Uniform Law Commission

July 5, 2023

The Terri Schiavo Life & Hope Network opposes the revisions to the definition of death under the Uniform Determination of Death Act (UDDA). These anticipated changes would permit an alarming range of subjectivity in determining death, permanently changing the Uniform Determination of Death Act.

The mission of the Life & Hope Network is to uphold human dignity through service to the medically vulnerable. We express this mission through public advocacy of essential qualities of human dignity, including the right to food and water, the presumption of the will to live, due process against denial of care, protection from euthanasia as a form of medicine, and access to rehabilitative care.

From its beginning, the criteria for death by neurological criteria “brain death” has been contentious, with numerous scenarios where a patient was wrongly declared brain dead, casting doubt on the finality and accuracy of the diagnosis. In the 18 years that the Life & Hope Network has been helping families, we have received dozens of calls from families in crisis after their loved one was diagnosed as brain dead in an astonishingly short period of time, sometimes within hours of being admitted to the hospital.

Indeed, these types of neurological diagnoses are difficult and complex. But perhaps the simple truth is that when patients sustain severe brain injuries, precious time is needed to administer treatment, allowing the brain the opportunity to heal instead of quickly determining that it is a hopeless and permanent condition.

Consider a July 2021 study published in *JAMA Neurology*, where UC San Francisco, Medical College of Wisconsin, and Spaulding Rehabilitation Hospital monitored nearly 500 patients with “moderate-to-severe traumatic brain injury (TBI).” Researchers concluded that decisions regarding the withdrawal of life-sustaining treatment for these types of patients should *not* be made in the early days following brain injury.

The *JAMA Neurology* study follows a 2018 review by the *American Academy of Neurology (AAN)*, updating their guidelines for disorders of consciousness. It was determined that current ICU practices are based on “flawed and outdated information.” The AAN recommended that for the first 28 days *after* a patient’s brain injury, physicians “must avoid statements” that suggest the patient has a poor or hopeless prognosis.

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Complicating matters even more, a 2016 study from *JAMA Neurology* found that not all the 508 U.S. hospitals surveyed were “100% compliant” with the AAN 2010 guidelines when determining brain death. The study also found “major variations in their policies” when diagnosing brain death. This means one patient can be treated as living at one hospital but diagnosed as brain dead at another.

Doctors must protect life until certain death – no evidence of biological life. If any changes are made to the text of the Uniform Determination of Death Act, it should demand a greater assurance that a person has died.

The Terri Schiavo Life & Hope Network urges the Uniform Law Commission to reconsider the revisions regarding the text of the UDDA and use language that would defend a person’s inherent dignity and maintain the opt-out for death by neurological criteria, rejecting all other changes to the UDDA.

Sincerely,



Bobby Schindler  
President