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TO: Members of the Uniform Law Commission

## Statement of the Life Legal Defense Foundation regarding proposed revisions to the UDDA

Life Legal strongly opposes revisions to the definition of death under the Uniform Determination of Death Act that would allow for a degree of subjectivity in the determination of death.

Life Legal has been involved either directly or tangentially in most, if not all, of the cases challenging brain death determinations that gave rise to the proposed changes to the definition of death. The individuals we represent have grave misgivings about declaring death solely on the basis of neurological criteria, especially in cases of children and young adults. In some cases, families have religious objections to the concept of brain death. However, in most cases, the misgivings arise when patients' family members and loved ones observe signs of life that appear incompatible with a declaration of death. These include the ability of patients to move their arms, legs, and even their heads; changes in blood pressure and other vital signs in response to the presence or absence of certain family members; healing from wounds and infections; absence of necrosis, organ failure and other predicted indicia of bodily decomposition; and for some, a knowing "sense" that their loved one is in some way still alive.

This "sense" was what drove Nailah Winkfeld's tenacious fight for the life of her daughter Jahi McMath. In the end, Nailah's intuition was correct. Oakland Children's Hospital seemed to have performed the brain death exam in accordance with accepted medical standards. However, several years later, neurologists and others who saw Jahi respond to basic commands acknowledged that, inexplicably, Jahi no longer met the criteria for brain death. She was not actually dead until she died of liver failure five years after she was issued a death certificate.

I personally witnessed a situation where a two-year old who had been declared brain dead turned his head when I called his name. Doctors brushed this off as a spinal reflex. In that same case, doctors refused to provide the toddler with a feeding tube, vehemently arguing that the child's digestive tract was "dead" and that he would never be able to assimilate food. The parents were able to have their son transferred to another hospital willing to do a gastrostomy. The toddler assimilated nutrition and hydration very well and quickly gained weight. While "dead," he grew several inches, recovered from an infection, was weaned off all vasopressors, and continued to move his head and limbs. His EEGs showed active, albeit slow, brain waves. It is understandable that the child's parents would question whether their son was in fact dead.

Cases like this cast doubt on the ability of doctors to determine death by neurological criteria with the objective, apodictic certainty required in matters of life and death. Introducing vague, subjective elements into the determination of death only serves to create further ambiguity and erodes trust in the medical profession.

Life Legal therefore respectfully urges the Commission to reject proposed revisions to the UDDA regarding the definition of death and to adopt only the proposed language granting accommodations, including notification, consent, and the right to opt out of the neurological criteria for brain death.

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