AMERICAN ACADEMY OF NEUROLOGY®

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January 30, 2023

Dear Commissioners,

We enjoyed meeting you in December and look forward to further discussion about potential revisions to the UDDA in February. The purpose of this letter is to reinforce our view that clinicians and hospitals need concrete, consistent legal guidance about management of objections to brain death determination. **A modification to the UDDA simply stating that hospitals must establish policies to address objections to brain death determination will not have a meaningful or useful impact on management of objections to brain death for patients, families, clinicians, or society.** Even if all hospitals establish policies about management of objections to brain death, it is likely each hospital will create a different policy, leading to conflict, moral distress, and frequent requests for transfer to other hospitals. Furthermore, review of existing hospital policies about management of objections to brain death demonstrate that they are vague and generally merely recommend clinicians "seek guidance" to determine how to address an objection. Inevitably, the number of cases brought to court will continue to escalate.

In this letter we summarize relevant data and guidance published by the American Academy of Neurology (AAN) regarding objections to brain death determination. These data document both the high prevalence of objections to brain death and the variation in hospital protocols about management of objections to brain death. We also summarize current AAN guidance to clinicians on management of objections to brain death. The force of the AAN's guidance would be significantly strengthened if concrete legal guidance were provided in a revised UDDA.

- **Clinicians are frequently asked to continue organ support after brain death determination.**
    - 47% of adult neurologists in the USA have been asked to continue organ support after brain death determination outside of organ donation (Organ support after death by neurologic criteria)
    - 61% of pediatric neurologists and intensivists in the USA have been asked to continue organ support after brain death determination outside of organ donation (Organ Support After Death by Neurologic Criteria in Pediatric Patients)
    - Survey data demonstrates that objections are attributed to 1) religious beliefs, 2) moral beliefs, 3) belief the patient could regain neurologic function, 4) lack of acceptance that the patient was dead because their heart was beating, 5) desire to await arrival of additional family members prior to discontinuation of organ support, 6) desire to delay the decision about organ donation, 7) desire to continue receiving social security benefits, or 8) perception that acceptance of death meant giving up on their loved one

- **Management of objections to brain death determination is highly variable across clinicians and hospitals:**
  - Clinician responses to objections to brain death in the aforementioned surveys included 1) discontinuation of organ support against the family's wishes, 2) discontinuation of organ support after the family no longer objected, 3) continuation of organ support for a set period of time, and 4) continuation indefinitely until circulatory-respiratory arrest
  - The most common reasons for continuation of organ support were desire to avoid 1) litigation, 2) upsetting the family, and 3) media coverage
  - In the setting of a hypothetical religious objection to brain death, ~50% of survey respondents would agree to continue nutrition/fluids and 20-40% would agree to continue medications, but only 15% would agree to start any new interventions after determination of death

- **A minority of hospital policies provide guidance on management of objections to brain death and those that do vary considerably in their recommendations:**
  - 22% of adult and 42% of pediatric US hospital brain death policies address management of objections to brain death (Prolonging Support After Brain Death: When Families Ask for More and Variability in Pediatric Brain Death Determination Protocols in the United States)
  - The most common recommendation in hospital policies about management of objections to brain death is to seek guidance, but a small number of policies recommend 1) continuation of organ support until circulatory-respiratory arrest, 2) discontinuation of organ support despite the objection, 3) obtaining a second opinion, or 4) transferring care
  - Among policies that recommend continuation of organ support in response to an objection to brain death, the length of time varies (a "brief compassionate period," determined by the clinician, until the family's objection is withdrawn, until a decision is reached by ethics/legal, 2 hours, 12 hours, 24 hours, 48 hours, until circulatory-respiratory arrest) as does code status during continuation of support
  - Policies provide inconsistent guidance on the legal time of death (53% do not address time of death, 37% indicate the time of brain death declaration is the time of death, 9% allow the family to choose the time of death, 1% indicate time of death is the time of death by circulatory-respiratory criteria)

- **Despite legal guidance about management of objections to brain death in California, Illinois, New Jersey, and New York, clinicians and policies in these accommodation states are just as unclear about how to manage objections as in non-accommodation states:**
  - Only one-third of adult neurologists in accommodation states and one-third of adult neurologists in non-accommodation states believe that the laws in their state provide clear guidance about how to handle an objection to brain death
  - Only half of adult neurologists in accommodation states and half of adult neurologists in non-accommodation states believe they have enough resources at their institution to handle an objection to brain death
  - Only one-quarter of pediatric neurologists in accommodation states and one-third of pediatric neurologists in non-accommodation states would feel comfortable handling an objection to brain death

- Half of hospital policies in accommodation states do not describe how to handle objections and to brain death and of those that do, the majority merely recommend seeking assistance from hospital administration/ethics committee/legal counsel/pastoral care/risk management

- **When asked how to improve management of objections of brain death determination, clinicians requested 1) changes to the law to guide and protect clinicians faced with objections to brain death and 2) legal guidance on what can/cannot and should/should not be done in the setting of objections to brain death determination.**
  - 15% of adult neurologists in the USA agreed that every state should legally allow for religious or moral objections to brain death
  - 13% of pediatric neurologists and intensivists in the USA agreed that every state should legally allow for religious or moral objections to brain death

- **The AAN provides the following guidance to members about how to manage objections to brain death determination** (Brain death, the determination of brain death, and member guidance for brain death accommodation requests):
  - "[T]he AAN believes that its members have both the moral authority and professional responsibility, when lawful, to perform a brain death evaluation including apnea testing, after informing a patient's loved ones or lawful surrogates of that intention, but without obligation to obtain informed consent. This position is analogous to the authority and responsibility historically granted to the medical profession to determine circulatory death without the requirement for additional informed consent."
  - "The AAN desires to provide lawful guidance for its members faced with requests for accommodation. These requests include objections to brain death determination or the withdrawal of organ-sustaining technology. The AAN strives to achieve reconciliation of the positions all stakeholders without undermining the professional responsibility of neurologists acting in the best interest of their patients."
  - "The AAN is respectful of and sympathetic toward requests for limited accommodation based on reasonable and sincere social, moral, cultural and religious considerations, recognizing that beliefs vary not only between but within religions, and understanding that such requests must be based on the values of the patient and not those of loved ones or other surrogate decision-makers."
  - "At the same time, the AAN acknowledges that there is no ethical obligation to provide medical treatment to a deceased person. In the United States, with the exception of New Jersey, there is no legal obligation to provide indefinite accommodation with continued application of organ-sustaining technology organ sustaining technology to the deceased. The AAN recognizes the potential for harm to the patient, the family, or other patients and the healthcare team from indefinite accommodation. These potential harms include mistreatment of the newly dead, deprivation of dignity, provision of false hope with resultant distrust, prolongation of the grieving process, undermining of the professional responsibility of the physician to achieve a timely and accurate diagnosis, and an anticipated societal harm arising from a negotiated and inconsistent standard of death."

- "The AAN encourages members to include provisions for management of requests for accommodation in institutional brain death protocols addressing the conditions and time frame for accommodation."
- "Despite its respect for cultural and religious perspectives, and its empathy for grieving loved ones, the AAN endorses the implicit position of the UDDA that death is a biological reality that may result from irreversible injury to the heart or brain. Accordingly, the AAN believes that death should be determined by criteria that can be objectively and uniformly assessed in order to demonstrate irreversible loss of circulatory or whole brain function, as supported by the President's Commission. Physicians are uniquely qualified and authorized by their training, experience and licensure to determine that death has occurred by either a circulatory or neurological mechanism, and are professionally obligated to make this determination in a timely and accurate manner."
- "The AAN suggests that when requests for indefinite accommodation occur, all authorized stakeholders in the welfare of the patient, including members of the medical team and designated administrative or legal institutional officials should be kept apprised of the situation. Involvement of others with recognized mediating skills, including clergy members, mental health professionals, palliative care or ethics consultants, should be considered."
- "The AAN recognizes that when attempts to reconcile disputes pertaining to indefinite accommodation fail, transfer of an individual to another facility, when lawful and feasible, represents a measure of last resort."
- "The AAN recognizes that when attempts to reconcile disputes pertaining to indefinite accommodation fail, unilateral withdrawal of organ sustaining technology (other than in pregnant females) over the objection of loved ones is acceptable, when supported by law and institutional policy, and represents a measure of last resort."

We appreciate your time and are happy to elaborate further on any of the information included here. We strongly believe that a revised UDDA should provide clear, concrete, and consistent legal guidance about management of objections to brain death determination. We look forward to ongoing discussions.

Sincerely,

Ariane Lewis, MD
on behalf of
the American Academy of Neurology

and

Matthew Kirschen, MD, PhD
on behalf of
the American Academy of Neurology