MEMORANDUM

TO: Uniform Law Commission Committee on Scope and Program

FROM: Samuel A. Thumma, Chair
Professor Nita A. Farahany, JD, Ph.D., Reporter
Study Committee on Updating the Uniform Determination of Death Act

DATE: June 16, 2021

SUBJECT: Final Report and Recommendation

Executive Summary

The Study Committee, having completed its work, recommends that -- with reservations and limitations noted below -- a drafting committee be established to consider updating portions of the Uniform Determination of Death Act.

Committee Members, Advisors, Observers and Staff

The Study Committee is made up of the following individuals: Commissioners K. King Burnett (Maryland); David M. English (Missouri); Jess O. Hale (Tennessee); Peter F. Langrock (Vermont); Bradley Myers (North Dakota); Martha T. (Marti) Starkey (Indiana); Eric Weeks (Utah); Steve Wilborn (Kentucky); Samuel A. Thumma (Arizona); Nita A. Farahany (Reporter); Mary (Molly) M. Ackerly (Division A Chair Member); Lisa R. Jacobs (Scope Liaison); Carl H. Lisman (President); Timothy J. Berg (Chair, Scope and Program Committee); Tim Schnabel (Executive Director); Arthur R. Derse (ABA Advisor); Chastity Sharp Grice (ABA Advisor) and Observers Jalayne Arias; Leila Barraza; Amanda Bentley; James L. Bernat; Richard Bonnie; Paul A. Byrne; Arthur Caplan; Alexander M. Capron; Lukas Chandler; Christy Coe; Christopher Dolan; David A. Fleming; Abbe R. Gluck; Henry T. Greely; David M. Greer; John Halperin; Megan Hille; Sarah C. Hull; L. Syd M. Johnson; Matthew Kirschen; Christof Koch; Ariane Lewis; David Magnus; Franklin G. Miller; Melissa Moschella; Diane L. Mossholder; Michael Nair-Collins; Jennifer Nelson-Dowdy; Marc R. Nuwer; David Orentlicher; Erin Paquette; Thaddeus Mason Pope; Steven R. Potter; Michael Potts; Katie Robinson; Lainie Friedman Ross; Abdulaziz Sachedina; William M. Sage; Maya Scott; Montey M. Self; Seema K. Shah; Daniel Alan Shewmon; Tara Sklar; Christina Woodward Strong; Daniel Sulmasy; Benjamin Tolchin; Robert D. Truog; Panos Varelas; Joseph L. Verheijde and Eelco Wijdicks. Katie Robinson, Leang Sou, Odessa Glaza and Lucy Grelle have provided wonderful staff support for the Study Committee.

Overview of the Study Committee's Work and Meetings

The Uniform Determination of Death Act (UDDA), included in full below, was promulgated by the ULC, and approved by the American Bar Association and the American Medical Association, in the early 1980s. Adopted in whole or in part in more than 40 states, the UDDA contains one substantive section ("Determination of Death") which states:

> "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."

The Study Committee's charge was to study the need for and feasibility of updating the UDDA. Although considering the entire UDDA, the work of the Study Committee largely focused on the "irreversible cessation of all functions of the entire brain, including the brain stem" portion of the first sentence (sometimes called in shorthand "brain death," which was a comparatively novel aspect of the UDDA) as well as the second sentence of this section.

Study Committee members were appointed in August 2020; the Reporter was named in September 2020, and Observers were added as the Study Committee began its work in earnest and throughout. Participants included individuals whose work in the 1970s prompted the UDDA and who were involved in crafting the UDDA. Significant historical and voluminous foundational materials were added to the Committee's Workspace on the ULC website throughout the effort.

The Study Committee met eight times, by Zoom, with meetings lasting about two hours each. The Committee's work included significant educational and perspective components. The first Study Committee meeting took place October 30, 2020. Following a welcome message from the Chair, the Reporter asked questions of the following invited individuals to provide information about the topics listed: (1) Alexander Capron (the history of the UDDA); (2) James Bernat (two independent criteria rather than single criterion for brain death with two sets of tests, irreversible vs. permanent, and "whole brain" criterion); (3) Ariane Lewis (neurological criteria for brain death and religious perspectives); (4) David Greer (medical history of brain death and death by neurological criteria, with a conceptual overview of the guidelines and clinical interpretation of "all functions of the entire brain" and variability in institutional practices) (5) Matthew Kirschen (brain death in pediatric populations, including discussing the need for consent); and (6) Christof Koch (research on the neural correlates of consciousness). This first meeting, which was presented through recordings (played twice to accommodate schedules), provided different information, from different perspectives and points of view, as important foundational reference information.

The second Study Committee meeting, held November 17, 2020, included recorded conversations between the Reporter and: (1) Allison Chen, sister of Angel Chen, who had passed away recently after she suffered a brain trauma; (2) Nailah Winkfield, Jahi McMath's Mother, who passed away after an extended legal battle over a declaration of brain death in California and who then was moved to New Jersey; and (3) Robert Truog, who discussed his perspective on the limitations of current standards for determining brain death and the approach followed for declarations of death in the United Kingdom.

The third Study Committee meeting, held January 13, 2021, included invited comments by and discussion with Galen V. Henderson, Director, Neuroscience Intensive Care Unit, Brigham & Women's Hospital, Boston/Assistant Professor of Neurology, Harvard Medical School, about the intersection of brain death/death by neurologic criteria and organ donation, and the dead donor rule. The meeting also involved an interactive discussion, including discussing the approaches used in

other countries. The Chair reported that, at a November 17, 2020 meeting, the Advisory Committee on Program Development and Management (ACPDM) of the Uniform Law Conference of Canada decided not to support taking up the UDDA in Canada.

The fourth Study Committee meeting, held February 26, 2021, included a report by the Chair and Reporter of a January 21, 2021 discussion with members of the Canadian Death Definition and Determination Committee. The meeting included invited comments by and a discussion with David Greer on The World Brain Death Project and Consensus Recommendations. The discussion underscored the variability in medical protocols and their applications for diagnosing brain death and a desire to promote consistency and uniformity across medical institutions. One important open issue was whether statutory amendments could enhance consistency in application of medical standards (reduce variations in clinical practice) while, at the same time, being adaptive to reflect ongoing advancements in medicine. The meeting also addressed issues in the states that have enacted the UDDA to attempt to identify areas of potential consensus, differentiation, and improvement.

The fifth and sixth Study Committee meetings, held April 2 and 26, 2021, continued the conversation about possible issues to address in any effort to revise the UDDA and what the Committee might recommend. The seventh and eighth Study Committee meetings, held May 24, 2021 and June 14, 2021, continued the conversation, including discussing prior drafts of this report.

Discussion

The Study Committee reached some conclusions with broad consensus, including:

- **The UDDA has had a broad influence in the United States and the World.** The UDDA was adopted broadly after its promulgation in the early 1980s. It is in place, in whole or in part, in more than 40 states in the United States. In the work of the Study Committee, it became apparent that the UDDA has had a significant influence in the laws throughout the world. In these ways, the UDDA has been a successful ULC product with broad influence. This is particularly true for the "brain death" definition, which is an important aspect of the UDDA. But "brain death" determinations in the United States represent a small number of all deaths. In recent years in the United States, "brain death" determinations represent about two percent of all hospital deaths. Ali Seifi, John Vincent Lacci & Daniel Agustin Godoy, *Incidence of brain death in the United States*, Clinical Neurology and Neurosurgery, Vol. 195 at 1 (Aug. 2020). In 2016, for example, there were 665,185 in-hospital determinations of death by cardio-pulmonary criteria in the United States compared to 15,405 determinations of death by neurological criteria, up from 12,575 such determinations in 2012. *Id.*

- **Portions of the UDDA do not align with current medical practice.** During the Study Committee's work, particularly in discussing the brain regions specified in the UDDA, there appeared to be a general consensus that clinical practice for diagnosing death by neurological criteria did not always directly square with the "entire brain, including the brain stem" as used in the UDDA. Put another way, there appeared to be a consensus that the legal definition of brain death in the UDDA and the medical practice or current generally accepted medical standards for brain death

determinations do not fully align. Similar concerns were expressed that the "irreversible cessation of circulatory and respiratory functions" criteria may not reflect current medical practice. The clinical process of diagnosing death is established and undertaken by the medical profession. The declaration of death, by contrast, is a legal process defined by the law. These two processes should align. There is good reason to revisit the language of the UDDA to see if it and medical standards can be better harmonized, to enhance transparency, to improve accuracy, and to improve public trust and understanding of determinations of death.

- **There is need for a revised UDDA.** There are several areas of ambiguity in the UDDA involving brain death/death by neurologic criteria, including: whether there should be two criterion for death versus a single definition with two ways to satisfy it (circulatory/respiratory or neurological criteria); whether the persistence of certain functions of the brain (e.g., hypothalamic functions) conflicts with the existing definition of brain death ("all functions of the entire brain, including the brain stem"); whether the term "irreversible" (cannot be reversed) cessation of function is ambiguous and if the term "permanent" (will not reverse) cessation of functions is more approriate; whether "accepted medical standards" should be specified by reference, through adaptive regulation, or other language; whether religious or other accommodations should be addressed; whether consent for the brain death determination (especially for apnea testing) should be required; who can declare brain death; and how many individuals are required to do so. Clarity around some or all of these issues may help promote uniformity of language and practice, as well as public understanding and acceptance of a revised UDDA.

- **It is unclear whether a revised UDDA would cause or result in uniformity in clinical practice.** It is unclear whether clarifying the statutory standard for the determination of brain death/death by neurologic criteria (either through statutory language or by specifying or including medical criteria) would cause or result in uniformity in clinical practice in applying the standard. The substantial need for any revised act to allow for ongoing advances in medicine counsels against a statutory adoption of a fixed medical standard, rather than one that is adaptive to such advances. However, statutory reference to accepted medical standards would likely guide medical standards, which may promote greater uniformity in clinical practice in the application of that standard, and greater accord between clinical practice and the legal standard for neurological criteria for death.

- **Innovation and advancement in medicine should be encouraged, not stifled.** It is important that any effort to revise the UDDA not inhibit medical innovation and advancement but encourage continuous innovation and advancement. Fundamental principles of medicine endure, but any effort to revise the UDDA must respond to evolving needs and requirements as well as innovation and advancement in science and medicine over time. Any drafting effort should encourage, not stifle, scientific innovation and advancement.

- **The need for outside-of-the-ULC champions.** Enactability would be a key component of any drafting effort. A revised UDDA would touch on the interests of many groups that may (or may not) be aligned, depending on the approach taken.

That is to be expected and is true, in some sense, for all ULC drafting projects. But from an enactability perspective, a drafting effort to revise the UDDA would need to involve organizational champions other than the ULC that are committed to the drafting process and to enacting a final product from various perspectives. Potential champions might include the American Academy of Neurology, the American Medical Association, the Society of Critical Care Medicine (including the Pediatric Section of that Society), the American Academy of Pediatrics, the World Brain Death Project, donation and transplantation organizations, insurers, practitioners, and academics as well as other interest groups. In addition, depending on the scope and substance of any drafting effort, opposition should be anticipated, including an effort to repeal the concept of brain death itself. This further demonstrates the need for champions supporting the effort outside the ULC. The Study Committee has sought to include Observers reflecting diverse interests and viewpoints, who also could serve as champions. There is, however, a clear need to continue to enlist outside-of-the-ULC champions to participate in any drafting effort and then work for enactment.

Along with these areas where there was consensus, the Study Committee identified areas of potential focus for a drafting committee in considering its recommendations. These areas involve four Categories of issues. These four Categories are listed below, with examples of statutory alternatives currently in place or being considered (with more proposals in scholarly articles in the Appendix to this report):

I. Medical Criteria to Determine Death Specified or Included:

- UDDA: "A determination of death must be made in accordance with accepted medical standards."
- Nevada: Determination of death must be "made in accordance with the applicable guidelines set forth in: (1) 'Evidence-based Guideline Update: Determining Brain Death in Adults: Report of the Quality Standards Subcommittee of the American Academy of Neurology,' published June 8, 2010, by the American Academy of Neurology, or any subsequent revisions approved by the American Academy of Neurology or its successor organization; or (2) 'Guidelines for the Determination of Brain Death in Infants and Children: An Update of the 1987 Task Force Recommendations,' published January 27, 2012, by the Pediatric Section of the Society of Critical Care Medicine, or any subsequent revisions approved by the Pediatric Section of the Society of Critical Care Medicine or its successor organization." Nev. Rev. Stat. § 451.007(2)(b)(1) & (2).
- New Jersey: Determination of death must be made "in accordance with currently accepted medical standards that are based upon nationally recognized sources of practice guidelines, including, but not limited to, those adopted by the American Academy of Neurology." N.J. Stat. Ann. § 26:6A-4 (West).
- Oklahoma proposed legislation: Directing a state "Board of Medical Licensure and Supervision" to promulgate rules based on its "consider[ation of] standards and guidelines issued by the American Academy of Neurology and the American Academy of Pediatrics, as well as by other widely recognized medical organizations or sources." ENGR. H. B. NO. 1896.

II. Irreversible vs. Permanent Cessation:

- UDDA: "[I]rreversible cessation," a term used in a majority of the states in the US as well as other countries.
- "Permanent" is used in a minority of other countries. Mexico ("Complete and permanent absence of awareness; Permanent absence of spontaneous breathing, and Absence of brain stem reflexes…"); *see also* Hungary ("entire, permanent, and irreversible cessation of functions of the brain, including the brain stem"); Poland ("permanent, irreversible cessation of brain activity (brain death)").
- Both "irreversible" and "permanent" are used in some other countries. Hungary ("entire, permanent and irreversible"); Poland ("permanent, irreversible cessation of brain activity (brain death)").

III. Brain Region Specified:

- UDDA: "[I]rreversible cessation of all functions of the entire brain, including the brain stem." *See also* UDDA Prefatory Note ("The 'entire brain' includes the brain stem, as well as the neocortex. The concept of 'entire brain' distinguishes determination of death under the [UDDA] from 'neocortical death' or 'persistent vegetative state.' These are not deemed valid medical or legal bases for determining death.").
- Cerebrum, cerebellum, and brainstem are used in some other countries. Croatia, Germany, and Norway.
- Brain stem is specified in some other countries. UK (NHS)("brain stem death"); India ("'brain-stem death' means the stage at which all functions of the brain-stem have irreversibly ceased"); Trinidad and Tobago ("irreversible cessation of all functions of the brain stem of that person").
- Cessation of all functions of the entire brain, without mention of the brain stem, is used in some states in the US and in some other countries. *E.g.*, Ariz. Rev. Stat. § 14-1107 ("A determination of death must be made in accordance with accepted medical standards"); *In re Haymer*, 450 N.E.2d 940, 945 (Ill. App. 1983) ("irreversible cessation of total brain function, according to usual and customary standards of medical practice"); Iowa Code § 702.8 ("irreversible cessation of spontaneous brain functions. Death will have occurred at the time when the relevant functions ceased"); La. Stat. Ann. § 9:111 ("an irreversible total cessation of brain function. Death will have occurred at the time when the relevant functions ceased"); N.C. Gen. Stat. § 90-323 ("an irreversible cessation of total brain function"); Tex. Health & Safety Code § 671.001 ("there is irreversible cessation of all spontaneous brain function. Death occurs when the relevant functions cease."); Finland ("brain function has totally ceased"); Italy ("irreversible cessation of all brain functions"); Qatar ("irreversible cessation of all functions of the brain").

IV. Other Issues:

The Study Committee discussed and considered additional issues that are not addressed in the UDDA but that other jurisdictions have included in their laws. These other issues at times implicate consideration of information provided by the individual or next of kin, or notice to the

individual's next of kin, and include:

A. Religious or Other Accommodations

1. New Jersey: "The death of an individual shall not be declared upon the basis of neurological criteria . . . when the licensed physician authorized to declare death has reason to believe, on the basis of information in the individual's available medical records, or information provided by a member of the individual's family or any other person knowledgeable about the individual's personal religious beliefs, that such a declaration would violate the personal religious beliefs of the individual. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria." N.J. Stat. Ann. § 26:6A-5.

2. Illinois: Requiring hospitals to "adopt policies and procedures to allow health care professionals, in documenting a patient's time of death at the hospital, to take into account the patient's religious beliefs concerning the patient's time of death." 210 Ill. Comp. Stat. § 85/6.24.

3. California: "A general acute care hospital shall adopt a policy for providing family or next of kin with a reasonably brief period of accommodation, [defined as "an amount of time afforded to gather family or next of kin at the patient's bedside"], from the time that a patient is declared dead by reason of irreversible cessation of all functions of the entire brain, including the brain stem. . . through discontinuation of cardiopulmonary support for the patient. During this reasonably brief period of accommodation, a hospital is required to continue only previously ordered cardiopulmonary support. No other medical intervention is required." "If the patient's legally recognized health care decisionmaker, family, or next of kin voices any special religious or cultural practices and concerns of the patient or the patient's family surrounding the issue of death by reason of irreversible cessation of all functions of the entire brain of the patient, the hospital shall make reasonable efforts to accommodate those religious and cultural practices and concerns." "[I]n determining what is reasonable, a hospital shall consider the needs of other patients and prospective patients in urgent need of care; [t]here shall be no private right of action to sue pursuant to this section." Cal. Health & Safety Code § 1254.4.

4. New York: Requiring hospitals to "establish and implement a written policy regarding determinations of death . . . [that must include]: (1) a description of the tests to be employed in making the determination; (2) a procedure for the notification of the individual's next of kin or other person closest to the individual . . .; and (3) a procedure for the reasonable accommodation of the individual's religious or moral objection to the determination as expressed by the individual, or by

the next of kin or other person closest to the individual." 10 N.Y.C.R.R. § 400.16(c)-(e).

B. Notice/Notification/Consent

1. Florida: Requires notice to the next of kin "as soon as practicable of the procedures to determine death" and requires medical records to reflect notice or attempts to provide notice. Fla. Stat. § 382.009(3).

2. New York: Requires hospitals to "make reasonable efforts to notify the individual's next of kin or other person closest to the individual" that a determination of death "will soon be completed." 10 N.Y.C.R.R. § 400.16(d).

3. Nevada: Stating "brain death" determination "is a clinical decision that does not require the consent of the person's authorized representative or the family member with the authority to consent or withhold consent." Nev. Rev. Stat. § 451.008.

C. Who can declare brain death/death by neurologic criteria?

1. Not specified.

2. At least one physician with specialization in a particular area of medicine.

3. Specific accreditation (e.g., Israel) or that the physician is not involved in the patient's care (e.g., Singapore) or in the procedures for obtaining organs if organ donation is involved (e.g., Canada, Israel, Qatar, US). *See also* https://capitol.texas.gov/BillLookup/History.aspx?LegSess=87R&Bill=HB4329 (pending in the Texas Legislature addressing some of these issues).

D. How many physicians needed to declare brain death/death by neurologic criteria? When specified, varies from 1-4 physicians.

The UDDA focuses on issues in Categories One, Two, and Three, but not Category Four. There was support on the Study Committee, in varying degrees, that a drafting committee examine issues in all four Categories. The consensus of a majority of the Study Committee was to support a drafting effort in the text of the UDDA for Categories One, Two, and Three. Although some expressed support for a drafting effort that would include Category Four issues, some discussion centered on excluding Category Four issues in the text of the UDDA. There was, however, support on the Study Committee that Category Four issues should be considered by a drafting committee in some manner—whether in the text or accompanying commentaries to any potential revision.

Recommendation

A majority of the Study Committee recommends that -- with reservations and limitations -- a drafting committee be established to consider updating portions of the Uniform Determination of Death Act to address the issues in Categories One, Two, Three, and Four above. This was not a unanimous recommendation by the Commissioners on the Study Committee. There was some concern expressed that proceeding with a drafting committee would open a pandora's box that could lead to, among other things, repeal of portions of the UDDA currently enacted in some states, sporadic enactment of a revised UDDA that would not yield uniformity, and other unintended consequences that could undermine the UDDA as it currently exists. An addendum, prepared by Commissioner Peter F. Langrock, further discussing these concerns is attached. There also was a suggestion that this report serve as an interim report with further efforts taken by the Study Committee in the coming months to continue to consider the issues. Acknowledging and respecting those views, a majority of the Study Committee recommends that -- with reservations and limitations -- a drafting committee be established to consider updating portions of the UDDA in all four Categories listed above. That recommendation, and these reservations and limitations, include what is discussed above as well as the following:

- **Build on the structure of the UDDA.**

  The UDDA is a short, successful ULC statute. Although in need of revision, the UDDA would provide helpful structure for a new drafting effort.

- **Determine whether mid-level principles and consensus could be achieved in attempting to draft a revised UDDA.**

  Although aspects of the current UDDA are not in accord with existing medical practice or current generally accepted medical standards, it is uncertain whether a revised UDDA could be drafted that would secure general consensus on clarified, revised, or improved standards. Whether that could happen may turn on whether there are mid-level principles that could gain consensus, recognizing that detailed specificity could result in impasse or disagreement on the appropriate standard.

- **Determine whether a revised UDDA could help enhance uniformity.**

  A revised UDDA would need to both be general enough to account for advances in science and medicine but also specific enough to provide for enhanced uniformity in practice. A revised UDDA would also need to account for these issues in a way that would be attractive to the states, given current enactments. Although some alternatives were discussed by the Study Committee (including reference to medical standards, which would change over time), that balance is particularly challenging given the nature of the UDDA. Properly implementing that balance, however, would need to be a foundational basis for a drafting committee crafting a revised UDDA.

- **Focus on enhanced transparency.**

  A revised UDDA that aligns with best medical practices, while allowing for future scientific developments, would provide an opportunity to use different terminology and focus and could enhance transparency in dealing with the determination of death. Approaches taken in the states and, particularly, in other countries would be instructive in that effort. Any drafting effort would benefit by considering these

issues in determining whether a revised UDDA could use better, or more refined, terminology to enhance transparency and understanding, including by the general public.

- **Focus on avoiding conflict and litigation.**

  Resolving issues created by the current UDDA in the litigation context, on a case-by-case basis, is a rare but perhaps increasing and, in any event, is a less-than-ideal way to resolve determination of death issues. An effort to revise the UDDA would need to take that into account by focusing on providing clearer answers that would avoid conflict and also help avoid the need to resort to litigation and case-by-case resolution through the judicial system.

- **Encouraging, and accounting for, innovation and advancements in medicine.**

  Fundamental principles of medicine endure, but any effort to revise the UDDA must respond to evolving needs and requirements as well as innovation and advancement in medicine over time. Any drafting effort should encourage, not limit, innovation and advancements in science and medicine.

- **Focus on how other current acts may impact the drafting effort.**

  The Study Committee identified some current uniform acts that may be relevant to, or provide guidance for, a drafting effort, including the Uniform Anatomical Gift Act (1968, last revised or amended in 2009), the Uniform Health Care Decisions Act (1993), and the Uniform Simultaneous Death Act (1993). *See also* Uniform Probate Code (2019); Uniform Real Property Transfer on Death Act (2009), Uniform Disposition of Community Property Rights at Death Act (1971, with an update currently in progress). It is suggested that a drafting committee consider how these acts may impact the effort.

- **Focus on enactability.**

  Any drafting committee focuses on enactability. But for a drafting effort to revise the UDDA, enactability should be a particularly significant focus. Along with identifying outside-of-the-ULC champions, as well as opponents, the effort would need to account for issues that (1) might result in significant opposition (both for a revised UDDA and the UDDA itself); (2) might result in a fiscal note in any proposed legislation; and (3) might result in reluctance by legislators in enacting or even proposing a revised UDDA. The Study Committee discussed these issues, but did not identify any specific resolution or plan, given that enactability would be a product of specific revisions a drafting committee might recommend.

- **Consider an interim "hard look" at an effort to draft a revised UDDA.**

  Given the challenges involved with drafting a revised UDDA, the Study Committee suggests an interim "hard look," perhaps a year into any drafting committee effort, to again assess the merit in continuing forward, in whole or in part. Such a hard look could further examine, critically and thoughtfully, considerations like (1) whether mid-level principles and consensus had been identified; (2) whether significant additional support (or opposition) had become apparent; (3) whether scientific or medical advances had changed the field; (4) whether legal developments had

significantly changed the issues involved; and (5) other relevant issues that had surfaced. In a sense, every drafting committee continuously evaluates such things. But given the significant challenges that would be faced by an effort to draft a revised UDDA, this hard look would be a particularly important interim step to determine whether proceeding forward with the drafting effort continued to be appropriate (and, if it did not, to end the effort).

Other Issues Considered

The Study Committee addressed many other issues not listed above that, from time to time, have been identified as relevant considerations for a study committee. Those issues include:

- The subject matter is appropriate for state legislation, both now and when the UDDA was promulgated in the early 1980s.
- It is unlikely that the United States Congress will act on the issues. It is also unlikely any proposal would require changes in federal law or federal regulations.
- The subject matter reflects the objectives of the ULC. The ULC addressed this subject in the UDDA, promulgated in early 1980s and adopted in some form in more than 40 states. An effort at updating the UDDA would advance the law on a subject the ULC has already addressed and has a significant presence.
- The UDDA, in many respects, provided significant benefits to the public through improvements in the law. There remains significant need for uniformity of the issues addressed in the UDDA as well as a need for consistency with the law and medical practice along with clarity, accountability, and transparency. Any revised UDDA would seek to do so.
- A new drafting effort would seek to maintain the integrity of well-balanced and well-settled law in areas traditionally governed by the states.
- The UDDA is a short act, with one substantive, but very important, section. Although it is likely a revised UDDA would not be shorter, it is unlikely that an effort to revise the UDDA would result in a lengthy proposed act.
- It is uncertain whether a revised UDDA would generate a fiscal note or otherwise impose a fiscal impact on the states. Depending on the specific text adopted, it is possible that a revised UDDA could generate a fiscal note.

Appendix

Kiaresh Aramesh et al., *An International Legal Review of the Relationship Between Brain Death and Organ Transplantation*, 29 J. Clinic. Ethics 31 (2018).

James L. Bernat et al., *Defining Death in Theory and Practice*, The Hastings Center Report (Feb. 1982).

James L. Bernat, *How the Distinction Between "Irreversible and "Permanent" Illuminates Circulatory-Respiratory Death Determination*, 35 J. Med. & Phil. 242 (2010).

James L. Bernat & Anne L Dalle Ave, *Aligning the Criterion and Tests for Brain Death*, 28 Camb Q. Healthc. Ethics 635 (2019).

David M. Greer et al., *Determination of Brain Death/Death by Neurologic Criteria: The World Brain Death Project*, 324 JAMA 1078 (and supplement 13) (2020).

Ariane Lewis et al., *Determination of Death by Neurologic Criteria Around the World*, 95 Neurology e299 (2020).

Ariane Lewis et al., *Determination of Death by Neurologic Criteria in the United States: The Case for Revising the Uniform Declaration of Death Act*, 47 J. L. Med. & Ethics 9 (2019).

Ariane Lewis, Richard J. Bonnie & Thaddeus Pope, *It's Time to Revise the Uniform Declaration of Death Act*, 172 Ann. of Int. Med. 143 (Jan. 21, 2020).

Franklin G. Miller & Robert D. Truog, *Death and the Brain*, in DEATH, DYING, AND ORGAN TRANSPLANTATION: RECONSTRUCTING MEDICAL ETHICS AT THE END OF LIFE (Oxford 2012).

Michael Nair-Collins et al., *Hypothalamic-Pituitary Function in Brain Death: A Review*, 31 J. of Intensive Care Med. 41 (2016).

Nikolas T. Nikas et al., *Determination of Death and the Dead Donor Rule: A Survey of the Current Law on Brain Death*, 31 J. Med & Phil. 237 (2016).

D. Alan Shewmon, *Statement in Support of Revising the Uniform Determination of Death Act and in Opposition to a Proposed Revision*, J. of Med. & Phil. (Advance article published online May 14, 2021) https://doi.org/10.1093/jmp/jhab014

Martin Smith, *Brain Death: The United Kingdom Perspective*, 35 Sem. in Neurology 145 (2015).

Robert D. Truog et al., *Understanding Brain Death*, 323 JAMA 2139-40 (May 1, 2020).

Eelco F.M. Wijdicks, *Brain Death Worldwide: Accepted Fact But No Global Consensus in Diagnostic Criteria*, 58 Neurology 20 (2002).

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Peter F. Langrock Addendum to Report of Determination of Death Study Committee

I am addressing this to the Scope and Program Committee and the Executive Committee regarding my concerns about going forward with the revised Determination of Death Act.

First of all, I must say that I have never been involved in a study committee that has worked any harder or had any better group of experts to advise them in connection with both the alleged flaws of the current act and the problems concerning both medicine and law going forward. Without question, our chair, Sam Thumma, has done an unbelievably good job in drawing this all together and his main report is totally comprehensive and fair. Saying that, it does not affect my concerns from the standpoint as a commissioner proposing uniform legislation.

First of all, I consider the present act as a major success for the conference. At the time we went forward with this act, there was a medical consensus that brain death should be adopted as the criteria as opposed to the cessation of the circulatory and pulmonary systems. This was especially important in terms of the growing transplant medical advances. In my opinion, there have been very few problems that have evolved as a result of the enactment.

From the study committee I understand there is a great deal of discussion within the medical community as to what is the appropriate standard and what is the appropriate protocol for declaring death. The present act basically leaves the medical decisions to the medical community. One of the dangers in re-drafting the act is that lawyers will be asked to make medical decisions which are not uniformly adopted by the medical community. I think that is a very dangerous position to be put into. Even if the drafting committee could come up with a singular definition or standard there are concerns within the study committee as to whether there should or should not be exemptions for religious or other consciences reasons. New Jersey has just such an exemption. The possibilities of exemptions seem to be endless. Within the Christian religions, there are numerous possible and controversial tacks that can be taken. These may very will differ from the Islamic interests in an exemption. How many other “conscience” objections that are out there we would likely find out. About five years ago I personally was asked to speak to the cyronics type society on the history of the Determination of Death Act. The cyronics society is as I learned a group of highly intelligent individuals who think in ways of maintaining the brain and the body in a condition to be revitalized in the future after medical advances that they believe will come will allow it. Their hope is for a rebirth and perhaps a perpetual life. There is also a much larger spiritualist community that believes in reincarnation and how they will come out in the situation I do not know.

What my concerns are is that once an act is drafted and promulgated we will find various interest groups throughout the country coming at the act from hundreds of different ways. My own opinion is that a new act would not promote uniformity but would have exactly the opposite effect.

Admittedly I have made a judgment that the concept of organ transplants after a medical determination of death is a positive social good. While I respect the potential religious and other conscience objections, I do not feel that society should have to underwrite them.

There is one other concern that arises in my mind and that is the rationing of medical services. Under Covid we almost reached the point where choices were going to have to be made as to who would be entitled to a ventilator and prioritize those in some manner. This could happen again and, quite frankly, I would not like to see a person who has a chance of surviving Covid or some other disease put behind somebody who is being sustained solely on the basis of a ventilator when they are really brain dead.

Certainly, there will be occasions of conflict in the future under the present act. I would suggest that no matter what is drafted there will still be areas of conflict. To me the amazing thing is that most all of these have been resolved under the present statutory scheme and I do not foresee a reduction of these conflicts under any other scheme.

I have tried to think what my 30 second or three minute elevator speech would be to a legislator asking me why they should adopt a new act. So far, nobody has provided me with information whereby I could comfortably answer in a positive fashion.

In analyzing the outlier cases in this area, I find that they have all focused on the emotions of living persons surrounding the brain-dead individual and little consideration is given to the person who has either permanently or irreversibly lost their brain function. I do not think protecting the sensibilities of these outlying family concerns is a positive social good when weighted against the problems these cause.

In summary, there are lives at stake and I do not mean those individuals who are, in effect, brain dead, but I am thinking of potential recipients of organs. I am uncomfortable with allowing these decisions to be resolved within the medical profession even though there may be different medical standards and protocols that occur both nationally and internationally. The fact that one hospital may differ from another hospital in protocol or one state's medical authorities differ from those in another state is acceptable to me. These seem to be working out in practice based upon the realities of the very drastic medical conditions of the individual that is called into question.

While I can visualize a drafting committee being a truly exacting intellectual activity in trying to draft narrow language to fit potential exemptions as being a great challenge, I am concerned that we may have the unintended consequence of undoing a very workable system.

Politically at the present time we see medical conditions whether in regard to voluntary euthanasia, Rowe v. Wade or vaccinations - all entering the political arena often with conflicting ulterior motives. I would not like to see that happen here.

I consider myself a team player and I am in full support of the work the committee has done in presenting this matter to the executive committee and the scope and program committee but I think both of those committees should look long and hard at the potential repercussions of going forward with this Act.

UNIFORM DETERMINATION OF DEATH ACT

Drafted by the

NATIONAL CONFERENCE OF COMMISSIONERS ON
UNIFORM STATE LAWS

and by it

APPROVED AND RECOMMENDED FOR ENACTMENT IN
ALL THE STATES

at its

ANNUAL CONFERENCE
MEETING IN ITS EIGHTY-NINTH YEAR
ON KAUAI, HAWAII
JULY 26 - AUGUST 1, 1980

With Prefatory Note

Approved by the American Medical Association
October 19, 1980

Approved by the American Bar Association
February 10, 1981

UNIFORM DETERMINATION OF DEATH ACT

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UNIFORM DETERMINATION OF DEATH ACT

PREFATORY NOTE

This Act provides comprehensive bases for determining death in all situations. It is based on a ten-year evolution of statutory language on this subject. The first statute passed in Kansas in 1970. In 1972, Professor Alexander Capron and Dr. Leon Kass refined the concept further in "A Statutory Definition of the Standards for Determining Human Death: An Appraisal and a Proposal," 121 Pa. L. Rev. 87. In 1975, the Law and Medicine Committee for the American Bar Association (ABA) drafted a Model Definition of Death Act. In 1978, the National Conference of Commissioners on Uniform State Laws (NCCUSL) completed the Uniform Brain Death Act. It was based on the prior work of the ABA. In 1979, the American Medical Association (AMA) created its own Model Determination of Death statute. In the meantime, some twenty-five state legislatures adopted statutes based on one or another of the existing models.

The interest in these statutes arises from modern advances in life-saving technology. A person may be artificially supported for respiration and circulation after all brain functions cease irreversibly. The medical profession, also, has developed techniques for determining loss of brain functions while cardiorespiratory support is administered. At the same time, the common law definition of death cannot assure recognition of these techniques. The common law standard for determining death is the cessation of all vital functions, traditionally demonstrated by an "absence of spontaneous respiratory and cardiac functions." There is, then, a potential disparity between current and accepted biomedical practice and the common law.

The proliferation of model acts and uniform acts, while indicating a legislative need, also may be confusing. All existing acts have the same principal goal - extension of the common law to include the new techniques for determination of death. With no essential disagreement on policy, the associations which have drafted statutes met to find common language. This Act contains that common language, and is the result of agreement between the ABA, AMA, and NCCUSL.

Part (1) codifies the existing common law basis for determining death - total failure of the cardiorespiratory system. Part (2) extends the common law to include the new procedures for determination of death based upon irreversible loss of all brain functions. The overwhelming majority of cases will continue to be determined according to Part (1). When artificial means of support preclude a determination under part (1), the Act recognizes that death can be determined by the alternative procedures.

Under part (2), the entire brain must cease to function, irreversibly. The "entire brain" includes the brain stem, as well as the neocortex. The concept of "entire brain" distinguishes determination of death under the Act from "neocortical death" or "persistent vegetative state." These are not deemed valid medical or legal bases for determining death.

This Act also does not concern itself with living wills, death with dignity, euthanasia, rules on death certificates, maintaining life support beyond brain death in cases of pregnant women or of organ donors, and protection for the dead body. These subjects are left to other law.

This Act is silent on acceptable diagnostic tests and medical procedures. It sets the general legal standard for determining death, but not the medical criteria for doing so. The medical profession remains free to formulate acceptable medical practices and to utilize new biomedical knowledge, diagnostic tests, and equipment.

It is unnecessary for the Act to address specifically the liability of persons who make determinations. No person authorized by law to determine death, who makes such a determination in accordance with the Act, should, or will be, liable for damages in any civil action or subject to prosecution in any criminal proceeding for his acts or the acts of others based on that determination. No person who acts in good faith, in reliance on a determination of death, should, or will be, liable for damages in any civil action or subject to prosecution in any criminal proceeding for his acts. There is no need to deal with these issues in the text of this Act.

Time of death, also, is not specifically addressed. In those instances in which time of death affects legal rights, this Act states the bases for determining death. Time of death is a fact to be determined with all others in each individual case, and may be resolved, when in doubt, upon expert testimony before the appropriate court.

Finally, since this Act should apply to all situations, it should not be joined with the Uniform Anatomical Gift Act so that its application is limited to cases of organ donation.

UNIFORM DETERMINATION OF DEATH ACT

§ 1. [Determination of Death]. An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

§ 2. [Uniformity of Construction and Application]. This Act shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this Act among states enacting it.

§ 3. [Short Title]. This Act may be cited as the Uniform Determination of Death Act.