MEMORANDUM

TO: Uniform Law Commissioners

FROM: Samuel A. Thumma, Chair
Eric Weeks, Committee Vice Chair
Professor Nita Farahany, JD, Ph.D., Reporter
Drafting Committee to Revise the Uniform Determination of Death Act

DATE: May 30, 2023

SUBJECT: Background for the June 9, 2023 Remote Informal Information Session.

We look forward to your comments on the current iteration of a draft revised Uniform Determination of Death Act (rUDDA) during the two-hour remote Informal Information Session to be held Friday, June 9, 2023. The draft will then be discussed on Wednesday, July 26, 2023 at the 2023 Annual Meeting. This will be the first time that a draft rUDDA has been considered by the Commission, and we look forward to those conversations on this important and challenging project.

The following Commissioners (five of whom served on the Study Committee) serve on the Drafting Committee: Turney P. Berry, Victoria Blachly, James Bopp Jr., David Clark, David M. English, Gail Hagerty, Peter Langrock, Bradley Myers, Jacob T. Rodenbiker, Larry L. Ruth and Martha T. Starkey, along with Division Chair Martin D. Carr. Joining in their incredible work are our ABA Advisor and more than one hundred Observers. We are grateful for their continuing service and commitment to this important and challenging project.

This memorandum is designed to (1) provide a brief historical background; (2) describe the Drafting Committee's charge; (3) provide a brief overview of our Drafting Committee and its work; (4) discuss the history and overview of our current draft and (5) highlight issues of particular interest for our discussions.

I. Brief Historical Background.

Although every ULC drafting effort is unique, the Uniform Determination of Death Act (UDDA) and rUDDA efforts are particularly so. Promulgated by the ULC in 1980, the UDDA then was approved by the American Medical Association (AMA) later in 1980 and by the American Bar Association (ABA) in early 1981. The UDDA was the product of a May 1980 meeting of representatives of the ULC, the AMA and the ABA in Chicago, Illinois. That meeting was prompted by similar, but not identical, efforts promulgated in the 1970s: (1) the Model Definition of Death (ABA Law and Medicine Committee 1975); (2) the Uniform Brain Death Act (ULC 1978) and (3) the Model Definition of Death Act (AMA 1979).

The UDDA, which has been adopted in whole or in part in more than 40 states and has had significant influence globally, 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."

A particularly significant aspect of the UDDA was part (2), addressing death by neurologic criteria, sometimes called "brain death," given the expansion of the use of mechanical ventilators and related technological advances in the years leading up to the UDDA.

In July 2020, the ULC Executive Committee approved a recommendation to create a Study Committee to consider the need for and feasibility of updating the UDDA. The Study Committee met eight times, by Zoom, with meetings lasting about two hours each. The Study Committee's Final Report, issued June 16, 2021, recommended that a drafting committee be established to consider updating portions of the UDDA. The Study Committee's Final Report can be found at https://www.uniformlaws.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=04b158fb-82e9-6ded-f799-9485aedd7e17&forceDialog=0.

As noted in that Final Report, the Study Committee reached some conclusions with broad consensus, including: (1) the UDDA has had a broad influence in the United States and the world; (2) portions of the UDDA do not align with current medical practice; (3) there is need for a revised UDDA; (4) is unclear whether a revised UDDA would cause or result in greater uniformity in clinical practice; (5) innovation and advancement in medicine should be encouraged, not stifled; and (5) there is a need for outside-of-the-ULC champions for any rUDDA effort.

In recent years, about 3,400,000 deaths are reported in the United States annually. See Jiaquan Xu, Sherry L. Murphy, Kenneth D. Kochanek & Elizabeth Arias, *Mortality in the United States, 2021*, NCHS Data Brief No. 456 (Dec. 2022) ("In 2021, a total of 3,464,231 resident deaths were registered in the United States—80,502 more deaths than in 2020."). "Brain death" determinations in the United States, however, represent a comparatively small percentage of all determinations of death.

First, "brain death" is determined in the hospital setting. As a percentage of all deaths in the United States, deaths in hospitals are reported as steadily decreasing from 39.7 percent in 2003 to 29.8 percent in 2017. *See* Sarah H. Cross & Haider J. Warraich, *Changes in the Place of Death in the United States*, N. Engl. J. Med. 381:2369-2370 (Dec. 12, 2019). During this same period, deaths at nursing facilities decreased from 23.6 percent to 20.8 percent, while deaths at home increased from 23.8 percent to 30.7 percent, and deaths at hospice facilities increased from 0.2 percent to 8.3 percent.

Focusing on deaths declared in the hospital setting, in recent years in the United States, "brain death" determinations are reported as representing about two percent of all hospital deaths. *See* Ali Seifi, John Vincent Lacci & Daniel Agustin Godoy, *Incidence of brain death in the United States*, Clinical Neurology & Neurosurgery, Vol. 195 at 1 (Aug. 2020). In 2016, for example, these authors reported 665,185 reported in-hospital determinations of death by cardio-pulmonary criteria

in the United States compared to 15,405 determinations of death by neurological criteria (about 2.23 percent) of the total. *Id.*

As discussed in the Final Report, a majority of the Study Committee recommended that a drafting committee be established to consider updating the UDDA to address issues in four categories: (1) medical criteria to determine death specified or included, given statutory alternatives currently in place or being considered in some jurisdictions; (2) whether "irreversible" (cannot be reversed) or "permanent" (will not be reversed) cessation is more appropriate; (3) the brain region specified for death by neurologic criteria, given alternatives currently in place in several jurisdictions; and (4) other issues (including religious or other accommodations; notice/notification/consent; who can declare brain death/death by neurologic criteria; and how many physicians are needed to declare brain death/death by neurologic criteria). 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 to the Final Report. There also was a suggestion that the Final Report serve as an interim report with further efforts taken by the Study Committee to continue to consider the issues. Acknowledging and respecting those views, a majority of the Study Committee recommended that -- with reservations and limitations -- a drafting committee be established to consider updating portions of the UDDA in all four categories listed above.

II. The rUDDA Drafting Committee's Charge.

Based on the Study Committee's Final Report, in July 2021, the ULC Executive Committee approved a resolution to form the rUDDA Drafting Committee. The rUDDA Drafting Committee's charge, in considering updating portions of the UDDA, is to address the issues in the four categories listed above as well as the following:

- build on the structure of the UDDA;
- determine whether mid-level principles and consensus can be achieved in attempting to draft a revision;
- determine whether a revision could help enhance uniformity;
- focus on enhanced transparency and accountability;
- focus on avoiding conflict and litigation;
- encouraging, and accounting for, innovation and advancements in medicine;
- focus on how other current acts may impact the drafting effort; and
- consider an interim "hard look" at an effort to draft a revised act.

III. The rUDDA Drafting Committee and its Work.

On parts of seven days from October 2021 to April 2022, the rUDDA Drafting Committee held Zoom meetings. The first meetings were educational and included interviews of various

invited individuals to discuss background information, including the history of the UDDA; various medical issues including two independent criteria rather than single criterion for brain death with two sets of tests, irreversible vs. permanent, and "whole brain" criterion; neurological criteria for brain death and religious perspectives; 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; brain death in pediatric populations, including discussing the need for consent; conversations with individuals whose family members had passed away after suffering brain trauma and who had a child pass away after an extended legal battle over a declaration of brain death of one individual in one state who was then moved to another state, limitations of current standards for determining brain death and the approach followed for declarations of death in the United Kingdom; and discussions of different philosophical approaches to death and their alignment or misalignment with death by neurological criteria.

The meetings that followed – two in March 2022 and two in April 2022 – built on these educational conversations and had a more traditional ULC drafting committee format, albeit virtually. After the meeting in April 2022, given the wealth of information shared, and considering our conversations, we asked for and received permission from ULC leadership to extend the timeline for our rUDDA Drafting Committee efforts. ULC leadership allowed the Drafting Committee an additional year to discuss and consider our work before presenting draft text for consideration by the ULC Commissioners broadly, both at an Informal Session and the Committee of the Whole at an Annual Meeting. This allowed us to continue our conversations, including in-person meetings, in our continued effort to determine whether mid-level principles and consensus can be achieved in trying to draft an rUDDA. It has also allowed us to track, and reference in part, the efforts of the Drafting Committee to revise the Uniform Health-Care Decisions Act, which is set for a second reading at the July 2023 ULC Annual Meeting.

The rUDDA Drafting Committee met in person, for the first time, for parts of two days in December 2022 (in Tucson, Arizona) and for two more days in February 2023 (in Washington, D.C.). These conversations have been incredibly rich and informative, recognizing there are deeply held, divergent points of view on many topics we are addressing. The conversations have appropriately taken different turns and directions over time. The current draft of an rUDDA comes from this rich and challenging debate and conversation.

IV. History and Overview of our Current Draft.

The current draft of an rUDDA represents the current version of a draft that has changed a great deal in the time the Drafting Committee has been working. Each of the components of the current draft has changed over time, and some concepts in this current draft first emerged during the second day of our most recent two-day meeting in Washington, D.C. (i.e., the most recent day the Drafting Committee met). ***None of the provisions in the current rUDDA draft submitted for discussion has been subject to a vote by the Drafting Committee. This context is critical to understand where the Drafting Committee is in its effort, and what the current rUDDA draft does, and does not, represent.***

With that preface, the following provides history and context for the sections of the current rUDDA draft.

Section 1: Title

The draft moves the title to Section 1 (from Section 3 in the UDDA), changing the heading from "Short Title" to "Title" and adding a place for the date, with no substantive change.

Section 2: Definitions

"Health care" is taken from the draft Uniform Health-Care Decisions Act for the May 30, 2023 Informal Session, with the references to mental illness and mental health care removed given the different context in this draft.

"Health-care institution" is a narrower version of the phrase used in the draft Uniform Health-Care Decisions Act for the May 30, 2023 Informal Session, reflecting that the phrase in the rUDDA is to define where a determination of death under Section 3(a)(2) can be made.

"Health-care professional" and "Physician" are taken verbatim from the draft Uniform Health-Care Decisions Act for the May 30, 2023 Informal Session.

"Surrogate" is a broader version of the term used in the draft Uniform Health-Care Decisions Act for the May 30, 2023 Informal Session, reflecting that the term as used in the rUDDA includes decision makers under the law of the state, regardless of whether the revised Uniform Health Care Decisions Act is adopted in that state.

"Record" and "State" are standard Commission definitions.

Section 3: Determination of Death

The current rUDDA draft contains two Options offered here for discussion. The Options in this draft are offered for discussion, recognizing a State would adopt one (and only one) Determination of Death provision

Option 1 is Section 1 of the UDDA (1980), as revised by the Committee on Style in 2023. It was discussed in conjunction with a "time to gather" provision, a "notification" provision, and a different version of an accommodation provision (which specified only that a hospital adopt a policy that clarifies how it would address objections to a determination of death pursuant to neurological criteria) that does not appear in the current draft.

Option 2 was identified, for the first time, on the second day of the Drafting Committee's most recent meeting in February 2023 (i.e., the last time the Committee met). It was drafted given the identification, during the first day of that Drafting Committee meeting, of a more expansive "accommodation" provision that specifies a right to opt out of a brain death determination reflected in Section 6(a) of the current draft rUDDA ("An individual may object to a determination of death

under Section 3(a)(2).”). Option 2 also changes “irreversible” to “permanent” for both circulatory and respiratory and brain death determinations. It also specifies, for the latter, that permanent coma, permanent cessation of spontaneous respiratory functions and permanent loss of brainstem reflexes are required for a determination of death by neurologic criteria. These criteria for the latter were first proposed and discussed at the Drafting Committee meeting on April 21-22, 2022.

Section 4: Time to Gather

This bracketed section of the current draft rUDDA would allow an enacting state to provide a reasonable amount of time to gather by the bedside of an individual who is determined to be dead by neurologic criteria under Section 3(a)(2). This draft Section 4 is similar to, but differs from, California law, which requires that “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.” Cal. Health & Safety Code § 1254.4. Although the Drafting Committee considered defining the length of time, or the outer duration of what “a reasonable amount of time” would be (i.e., “not to exceed . . .”), there was no consensus for that approach, and it is not included in this draft Section 4.

Section 5: Notification

This bracketed section of the current draft rUDDA would allow an enacting state to require health-care institutions to make reasonable efforts to notify the individual’s surrogate before the clinical evaluation for the determination of death under Section 3(a)(2) begins. This type of notification is similar (but not identical) to New York and Florida law. *See* 10 N.Y.C.R.R. § 400.16(d); Fla. Stat. § 382.009(3). The Section 5(a) “Clinical evaluation for the determination of death” definition is unique to the rUDDA.

Section 6: Accommodation

This bracketed section of the current draft rUDDA, which was identified, for the first time, on the first day of the Drafting Committee’s most recent meeting in February 2023, would be more permissive of objections to death by neurological criteria than any existing statutory approach, to allow an enacting state to permit an individual (either directly or through the individual’s surrogate) to object to a determination of death under Section 3(a)(2). A few states have provisions expressly addressing objections, albeit more narrowly circumscribed. The most expansive is New Jersey, which states: “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. Illinois, by contrast, requires 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. California law provides "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." Cal. Health & Safety Code § 1254.4; *see also* 10 N.Y.C.R.R. § 400.16(e)(3) (requiring hospitals to have a written policy regarding determinations of death that "shall include," among other things, "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").

Sections 7, 8 and 9

These sections of the current draft rUDDA contain standard provisions used by the Commission.

V. Reference Materials.

The Drafting Committee has amassed substantial foundational materials to date in its consideration. Uniform acts that have been referenced in the effort include the Uniform Health Care Decisions Act (1993 and as currently being amended); the Uniform Disposition of Community Property Rights at Death Act (2021); the Uniform Probate Code (1969, last revised or amended 2019); the Uniform Anatomical Gift Act (1968, last revised or amended in 2009); the Uniform Real Property Transfer on Death Act (2009) and the Uniform Simultaneous Death Act (1993).

VI. Issues of Particular Interest in the Informal Discussions.

Particularly given that this is the first time an rUDDA draft has been submitted to the Commission, we are interested in a wide variety of input from Commissioners. More specifically, however, we would welcome comments and questions on the following issues of particular interest:

1) Views on the merits, reservations and differences between Option 1 and Option 2 of Section 3(a) and whether they enhance transparency and accountability.
2) Whether specifying or further defining "accepted medical standards" by referencing organizations adopting such standards, in their counterparts to Section 3(b), would be beneficial.
3) Views on the concepts reflected in Sections 4 ("Time to Gather"), 5 ("Notification") and 6 ("Accommodation") from enactability, uniformity, transparency, accountability, confidence and other perspectives, recognizing only a few states have enacted such provisions.
4) Would offering bracketed language substantially different than current variation among the states be likely to spur greater conflict and litigation or greater uniformity in states?
5) Recommendations for next steps in the efforts, given our struggle, three years into the project, to identify mid-level principles and consensus for an rUDDA as it pertains to death by neurologic criteria.

6) The Study Committee recommended taking a "hard look" at its efforts to decide whether to proceed. Given our current progress, by what criteria should we assess the merits of proceeding with an rUDDA at this point?
7) Are there other options the Drafting Committee should consider, including whether it might make sense to "pause" the project to see if additional developments (medical, legal or otherwise) could better advance possible uniformity?

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In closing, we wish to thank those involved in the Drafting Committee process. We appreciate the willingness of the participants to serve, to listen carefully, to share thoughtfully and to help work hard to craft an rUDDA. It is a mighty challenge, and we are delighted that the active participants are a part of that effort.