

MEMORANDUM

TO: Commissioners, Advisors and Observers serving on the Uniform Law Commission's Drafting Committee to Revise the Uniform Determination of Death Act

FROM: Samuel A. Thumma, Committee Chair
Eric Weeks, Committee Vice Chair
Professor Nita A. Farahany, JD, Ph.D., Committee Reporter

DATE: September 23, 2021

SUBJECT: Welcome, Background, Committee Charge, Committee Overview, Scheduling and Reference Materials.

Welcome to the Uniform Law Commission's Drafting Committee to Revise the Uniform Determination of Death Act. We look forward to working with you on this important project.

Our Drafting Committee is just beginning its work. This memorandum is to provide some context and background, as well as a rough schedule for our work for the first year of our effort, and to provide some context for our work and how the Drafting Committee is structured. This memorandum is designed to (1) provide some historical and background information; (2) describe the Drafting Committee's charge; (3) provide a brief overview of our Drafting Committee; (4) discuss scheduling and (5) include some reference information.

I. Historical and Background Information.

The Uniform Determination of Death Act (UDDA) 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 UDDA has had a significant influence globally and for laws adopted in other countries.

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. ULC Study Committees review an area of law in light of defined criteria and recommend whether ULC should proceed with a draft on that subject. The UDDA Study Committee was made up of nine ULC Commissioners; a Reporter; ABA Advisors and about 50 Observers. The charge was to study 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 -- with reservations and limitations noted in that Final Report -- a drafting committee be established to consider updating portions of the UDDA. A copy of that Final Report, which also attaches the UDDA, is **Attachment 1** to this memorandum.

II. Our Drafting Committee's Charge.

Based on the Study Committee's Final Report, in July 2021, the ULC Executive Committee approved a resolution to form our Drafting Committee. ULC drafting committees are charged with drafting statutes and related text on a specified area of law for state legislatures to consider after they are promulgated. Drafting committees typically meet two times a year, for two years, during which time the in-progress draft is also presented for a line-by-line reading and debate at ULC Annual Meetings held each July.

The work of the Drafting Committee will build on the work of the Study Committee, including in particular the Four Categories of Issues and the Discussion in **Attachment 1**. As reflected in that Final Report, the Drafting Committee's charge, in considering updating portions of the UDDA, is to address issues in four categories: (1) medical criteria to determine death specified or included; (2) irreversible vs. permanent cessation; (3) brain region specified; 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). The charge includes that our Drafting Committee

- 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. Our Drafting Committee.

As noted, the Study Committee had nine Commissioners; a Reporter; ABA Advisors and about 50 Observers. Our Drafting Committee has 13 Commissioners (five who served on the Study Committee); a Reporter; more than 50 Observers (some who volunteered recently) and ABA Advisors to be added. The current roster is **Attachment 2** to this memorandum. Each of these groups serves somewhat different functions. Among many other things, the Commissioners are the individuals who decide what the Drafting Committee will recommend, including voting on what to recommend (if consensus is not reached and any votes are needed). Observers and ABA Advisors are incredible resources for the Drafting Committee, and bring valuable expertise to inform the work of the Commissioners. The current ULC Observers' Manual, which provides helpful perspective on the important role of Observers, is **Attachment 3** to this memorandum; the current (and comparable) ULC ABA Advisors' Manual is **Attachment 4**.

Duke Professor Nita A. Farahany, JD, Ph.D., who served as the Reporter for the Study Committee, has agreed to serve as Reporter on our Drafting Committee. Nita is a leading scholar on the ethical, legal, and social implications of emerging technologies. She is the Robinson O. Everett Professor of Law & Philosophy, the Founding Director of Duke Science & Society, Chair of the Duke MA in Bioethics & Science Policy, and principal investigator of SLAP (Science, Law & Policy) Lab. Among many other things, Nita has served as an appointed member on the Presidential Commission for the Study of Bioethical Issues from 2010 to 2017 and received the 2021 Distinguished Teaching Award at Duke Law School. Nita will continue to bring so much to the project, particularly given the interdisciplinary nature of our effort. More information about Nita can be found at <https://law.duke.edu/fac/farahany/>

IV. Scheduling Information.

During its work, the Study Committee considered a significant amount of foundational material, including some interviews that Nita conducted on various issues. Because a majority of the Commissioners on the Drafting Committee were not members of the Study Committee, we will use an atypical, dual-track schedule for the Drafting Committee effort throughout the rest of 2021. Our hope is that this effort will allow all to have the benefit of that foundational background as we continue our work in earnest, in a more traditional method by discussing draft text, in the first part of 2022.

Scheduling information for the next year can best be viewed working backwards from the 2022 ULC Annual Meeting. Given the charge of our Drafting Committee, we will need to be able to provide initial draft statutory text for consideration at a line-by-line reading at the 2022 ULC Annual Meeting, scheduled for July 8-14, 2022 in Philadelphia, PA. (That will be the first of two ULC Annual Meeting readings, the second of which likely will occur in July 2023). Before a draft act can be read and considered at the Annual Meeting, we will need to provide draft text for the ULC's Style Committee to review at its May 2022 meeting. For that to occur, we will need to have initial draft text (and perhaps a prefatory note and comments) to submit for consideration by the ULC in late April or early May 2022. These deadlines help instruct the work of the Drafting Committee and our schedule.

Having started at the end, we have set forth the following schedule for the rest of 2021. In particular, given the new Commissioners on the Drafting Committee that were not on the Study Committee, and because we have welcomed new volunteer Observers, we have decided on a parallel path effort through the rest of 2021 as follows (recognizing separate polling for dates, invitations and reminders will follow for each of these):

A. For all Drafting Committee participants (and particularly for those who were not involved with the work of the Study Committee), we will have three meetings during the remainder of 2021, each via Zoom, as follows:

1. The first meeting will be held on a date to be determined in October 2021 on two different times that day (to accommodate schedules) and will last

approximately two hours. At this meeting, after a brief welcome message and discussion of scheduling, we will play recorded conversations between Nita and (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).

2. The second meeting will be held on a date to be determined in November 2021 on two different times that day (again, to accommodate schedules) and will last approximately one hour. At this meeting, we will play recorded conversations between Nita and (1) Allison Chen, sister of Angel Chen, who had passed away 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 discusses his perspective on the limitations of current standards for determining brain death and the approach followed for declarations of death in the United Kingdom.

These first two meetings are designed to provide different information, from different perspectives and points of view, as important foundational reference information, as we did during the work of the Study Committee.

3. The third meeting, to be held at a date to be determined in of December 2021, via Zoom, will last approximately two hours. This will be a “live” meeting where we will begin to discuss the issues listed in the Study Committee’s June 16, 2021 Final Report, including the Four Categories of Issues, likely drawing on some Observers to address questions and issues Commissioners may have at that time.

B. A Parallel Drafting Effort.

Recognizing the need to have draft text for all Drafting Committee participants to consider in January 2022, we (Nita, Sam and Eric) will be undertaking a parallel drafting effort during the rest of 2021. Along with looking at what the various jurisdictions have adopted following the promulgation of the UDDA in the early 1980s, there has been a wealth of scholarship addressing the UDDA. Our Observers include a significant number of those authors. So we would welcome specific textual suggestions for that effort from each of you. While we always welcome scholarly considerations of these issues, we are specifically inviting practical textual recommendations for this effort. To that end, please send to us any specific textual suggestions you would like to be considered in our drafting effort and please also let us know if you would like to briefly discuss the suggestion with the three of us. If so, we could schedule a time to briefly discuss, via Zoom, your proposal in our parallel drafting effort.

The product of this parallel drafting effort will be draft text for the Drafting Committee to consider at its first meeting in 2022. We will account for the specific textual suggestions that we receive and identify. The specific content of the draft, however, is unknown and unknowable right now. Moreover, the draft that we circulate for consideration by the Drafting Committee participants will be the product of the three of us, not the product of the Drafting Committee or any other participants. Put another way, the draft will be a first draft for the Drafting Committee to consider.

C. Meetings In 2022.

We anticipate having two Drafting Committee meetings in 2022 before May 2022. As noted, the purpose of those meetings will be to discuss the draft text prepared during the parallel drafting effort discussed above, and to then account for changes, suggestions, additions, deletions, etc., along the way. Those meetings have not yet been scheduled, so please stay tuned for polling as we try to schedule them in a manner that can work for the most participants.

V. Reference Materials.

The Study Committee amassed substantial foundational material that it considered. We will make sure those materials are available, particularly for those who did not participate in the Study Committee.

As noted in the Study Committee's Final Report, other uniform acts that may be relevant to, or provide guidance for, a drafting effort include 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). Those acts also can be located on the ULC website (www.uniformlaws.org) and we would commend them to you.

Please also forward to us any new or additional articles that you believe would help the work of the Drafting Committee.

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In closing, thank you again for serving on this Drafting Committee. As we begin our effort, we appreciate more than you can know your willingness to serve, to listen carefully, to share thoughtfully and help work hard to craft a revised statute. We look forward to that challenge, and are delighted that you are a part of it.