



Wisconsin Commissioners
Uniform Law Commission
111 N. Wabash Avenue
Suite 1010
Chicago, Illinois 60602

Dear Wisconsin Uniform Law Commissioners:

On behalf of the University of Wisconsin Hospitals and Clinics Authority (UW Health), we are writing ahead of the Uniform Law Commission's meeting on June 9th to discuss proposed revisions to the Uniform Determination of Death Act. While we at UW Health are generally supportive of efforts to finetune legal definitions, we are worried by much of the language included in this draft and want to make you aware of our concerns.

UW Health includes the academic health care entities of the University of Wisconsin-Madison, a large network of primary and specialty care clinics throughout south-central Wisconsin and beyond (this network provides access to over 1,200 clinicians), and, UW Organ and Tissue Donation (OTD). UW OTD is one of only a few hospital-based organ procurement organizations in the country, consistently ranking in the Top 10 programs in the U.S. The OTD team works with critical care professionals at over 100 partner hospitals in order to facilitate the gift of organ donation and transplantation, including allocation, surgical recovery and preservation, education and support to donor families, and more. They manage every aspect of care for deceased donors and families, including through the end-of-life process, organ recovery and preservation, research and education. In calendar year 2022, the UW OTD served 162 deceased organ donors and facilitated 501 life-saving transplants. For over 50 years, the OTD is proud to have been devoted to serving deceased organ and tissue donors and their families; staff are known for their expertise, innovation, and commitment to service across the country.

As you know, the Uniform Declaration of Death Act (UDDA) has been in place since the 1980s. The UDDA gives legal standing to the determination of death by neurologic criteria, or "brain death." While OPOs, such as the UW OTD, do not declare brain death (this is the purview of physicians, medical examiners, and other healthcare providers), OPOs *do* verify that death has been declared pursuant to state law and hospital protocols.

The meeting on June 9 is the first opportunity for all Commissioners to read and discuss the updated draft, and it is also an opportunity for healthcare systems and hospitals such as UW to review and give input. While OPOs did not request the update, as a general matter, UW Health would support certain changes that would provide additional legal clarity around medical standards related to the brain death declaration process. For example, UW Health supports the proposed changes in Section 1 of the draft that would remove reference to the "brain stem" and the modifications around the words "irreversible" and "permanent." We believe that these changes are helpful for clarity and are in line with current medical standards, especially with regard to the addition of the word "permanent." We thank the committee for proposing these changes.

However, it appears that the updated draft contains much broader policy changes than simply streamlining definitions, and this is where UW Health wishes to express concern:

Provisions in the Draft

Section 4. Notification

The draft states: *Before a health-care professional begins the clinical evaluation for the determination of death of an individual under Section 3(2), a health-care institution shall make reasonable efforts to notify the individual's surrogate that the evaluation will soon begin.*

While we do not object to encouraging health-care institutions to notify an individual's surrogate in these circumstances, and we acknowledge this as a best practice in general, we do not feel that a state legislative mandate will best achieve this goal. Hospitals and physicians have policies, processes and procedures that spell out who we speak with, about what, and when; these processes cover all diagnoses and procedures. They are situation and family dynamic specific. While most clinicians (usually the attending physician or their designee) would provide notice as a course of practice, we are concerned that mandating it in this way could impede the exercise of judgment by the practitioner responsible for evaluating the patient, which could be seen as undermining the role of the practitioner and serve as a worrying precedent for the future. In addition, we are concerned that mandating "reasonable" effort, which we believe to be an unclear standard, will cause unnecessary delay.

Section 5. Time to Gather

The draft states: *After the individual is determined to be dead under Section 3(2) but before the discontinuation of circulatory and respiratory support of the individual, the health-care institution shall allow a reasonable amount of time for those designated by the individual's surrogate to gather at the individual's bedside.*

While UW Health understands how important it can be for families to be together at the time preceding, during, and immediately after death, and in fact the OTD makes every effort to ensure that this is possible, we also understand that this is not always practicable. UW Health serves a diverse population of patients; many of them have family members throughout the world or have traveled to Wisconsin from outside the U.S. themselves (eg: Wisconsin has a large population of study abroad students, and have had cases where a student has died while in our state). Sometimes family and friends are simply unable to travel to the bedside, whether it is due to location, financial constraints, relationship status, or other reasons. Instead, we would urge the ULC to consider the specifics in each patient's individual case. We believe that staff should support each patient and family based on their needs, not based on such a broad standard that may not be the best outcome for every case. If the ULC keeps this provision in the draft, we suggest that at the very least language is added to explain the options health-care providers have should the family be unable to attend the bedside. It has not been our observation that this aspect of end-of-life care is identified by patients as unsatisfactory, and we question the need for a legislative mandate surrounding these most intimate moments in a family's end of life care.

Section 6. Accommodation

The draft states: *A health-care institution shall adopt a policy in a record that sets forth the reasonable efforts it will make to accommodate [the personal] objections by the individual to a determination of death pursuant to Section 3(2). Any such objections must be expressed in the individual's medical records or through information provided to the health-care institution by an individual's surrogate. (1) The policy shall allow the individual to choose that a determination of death of the individual be made solely*

pursuant to Section 3(1). (2) The policy shall provide that any objections be made before beginning the clinical evaluation for the determination of death pursuant to Section 3(2) must be made before beginning that determination.

While we understand the desire to be as respectful to patient preferences as possible, and in fact share that goal, we are unaware of any instances in which an advance directive or other legal document has indicated an individual's objection to brain death. In addition, we are concerned that making exceptions based on individual beliefs related to brain death as a concept could create confusion and potentially even call into question the validity of any/all brain death diagnoses. Given that brain death is a medically accepted standard, we are very concerned about the impact of this.

In addition, we are even more concerned about accommodations for surrogate decision-making. Relying on a surrogate to make such a momentous decision, rather than trained health care professionals would very likely be based on the surrogate's individual views of brain death- not the patient. In fact, some courts have unfortunately had to grapple with these issues, with the Nevada legislature even taking the step to create precedent establishing that families do not have to consent to brain death following a lengthy legal battle.¹

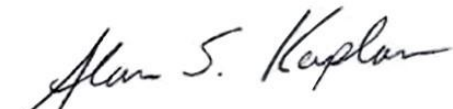
Other Concerns

During discussion over these proposed changes, the topic of family consent has been raised. UW Health believes that family or surrogate consent should not be required in order to initiate an exam to assess neurological status or determine death by neurologic criteria. The exam presents no risks to the patient, but delay in performing the exam could result in grave harm to the patient.

In addition, UW Health would be unable to support any provision that would allow families to opt-out of neurologic death. Neurologic death has been an established fact for over 40 years and is accepted by various medical associations, including the American Academy of Neurology and the Society of Critical Care Medicine. Allowing opt-out of neurologic death standards would only serve to increase uncertainty at the end of life, which is already a time fraught with emotion and stress. In addition, allowing families to make this decision could undermine the patient's desire to make an altruistic gift at the end of life. Finally, should some states accept an opt-out, while others to not, we are concerned that not only will each patient death be uncertain, but that conflicting standards across the country could cause a destabilization of organ donation across the board- with patients quite literally declared dead in one state but not another.

Thank you for the opportunity to provide these comments. Should you have any questions, concerns, or want to discuss any of these topics in more detail, please contact Michelle Seger at mseger@vennstrategies.com.

Sincerely,



Alan S. Kaplan, MD
CEO of UW Health

¹ <https://www.rgj.com/story/news/2016/03/25/contested-death-aden-hailu/82269006/>;
<https://www.leg.state.nv.us/App/NELIS/REL/79th2017/Bill/5570/Text>