

# Potential Threats and Impediments to the Clinical Practice of Brain Death Determination

The UDDA Revision Series

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## Abstract

The Uniform Determination of Death Act (UDDA) revision series in *Neurology*® originated in response to the plan of the Uniform Law Commission to create a revised Uniform Determination of Death Act (rUDDA) to address contemporary controversies associated with brain death/death by neurologic criteria (BD/DNC) determination. This article contextualizes these, and other, controversies and reviews the extent to which they represent potential threats and impediments to the clinical practice of BD/DNC determination. It also explains the reasons that our rapidly evolving understanding of the brain's ability to recover from injury should not influence the clinical practice of BD/DNC determination. Finally, it explores the myriad ways in which the American Academy of Neurology has addressed potential threats and impediments to the clinical practice of BD/DNC determination and the implications potential changes to the UDDA may have on the future of the clinical practice of BD/DNC determination.

## Introduction

The Uniform Determination of Death Act (UDDA) revision series in *Neurology* originated in response to the plan of the Uniform Law Commission (ULC) to create a revised Uniform Determination of Death Act (rUDDA) to address contemporary controversies associated with brain death/death by neurologic criteria (BD/DNC) determination.<sup>1-10</sup> Although other articles in this series use the term “brain death,” the term “brain death/death by neurologic criteria” (or “BD/DNC”) is used in this article, which concludes the series, to both embrace the colloquial term and reinforce its equivalency to death by circulatory-respiratory criteria, consistent with the approach taken by the World Brain Death Project (WBDP), a 2020 international consensus statement on BD/DNC determination.<sup>11</sup> Other articles in this series examined (1) the ideal brain criterion of death, (2) the need for cessation of hypothalamic neurosecretory function before BD/DNC determination, (3) the use of the term “irreversible” vs “permanent” to characterize the cessation of function required for BD/DNC determination, and (4) the need for informed consent before BD/DNC evaluation.<sup>2-10</sup> Although it is unknown, as of yet, whether, and how, the rUDDA will address each of these controversies, this article contextualizes these, and other, controversies and reviews the extent to which they represent potential threats and impediments to the clinical practice of BD/DNC determination. It also explains the reasons that our rapidly evolving understanding of the brain's ability to recover from injury should not affect the clinical practice of BD/DNC determination. Finally, it explores the myriad ways in which the American Academy of Neurology (AAN) has addressed potential threats and impediments to the clinical practice of BD/DNC determination and the implications potential changes to the UDDA may have on the future of the clinical practice of BD/DNC determination.

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## Glossary

AAN = American Academy of Neurology; AAP = American Academy of Pediatrics; ACTH = adrenocorticotrophic hormone; ADH = antidiuretic hormone; ANA = American Neurological Association; BD/DNC = brain death/death by neurologic criteria; CNS = Child Neurology Society; DoC = disorders of consciousness; FSH = follicle-stimulating hormone; GH = growth hormone; ICU = intensive care unit; LH = luteinizing hormone; NCS = Neurocritical Care Society; RUDDA = revised Uniform Determination of Death Act; SCCM = Society of Critical Care Medicine; TSH = thyroid-stimulating hormone; UDDA = Uniform Determination of Death Act; ULC = Uniform Law Commission; WBDP = World Brain Death Project.

## How Do Controversies Related to BD/DNC Determination Influence the Clinical Practice of BD/DNC Determination?

The decision to create the rUDDA was prompted by concerns of physicians, health law experts, ethicists, and philosophers after a number of highly publicized lawsuits related to BD/DNC determination (Figure 1).<sup>1</sup> These concerns impugned (1) the clarity of the UDDA, (2) its concordance with accepted medical standards, and (3) its silence on both (a) the need (or lack thereof) for informed consent before BD/DNC evaluation and (b) the appropriate legal response to religious or moral objections to BD/DNC.

While many controversies related to BD/DNC determination do not directly influence the clinical practice of BD/DNC determination, they are not exclusively siloed in academic debates. Lawsuits objecting to BD/DNC determination raised these controversies, which has implications for patients, surrogates, health care professionals, and society. Furthermore, potential revisions to the UDDA to reconcile these issues could affect the clinical practice of BD/DNC determination.

## How Would a rUDDA Requirement to Demonstrate Cessation of Hypothalamic Neurosecretory Function Affect the Clinical Practice of BD/DNC Determination?

The UDDA requires cessation of “all functions of the entire brain, including the brainstem” to declare BD/DNC.<sup>12</sup> The most recent BD/DNC guidelines (the 2010 AAN BD/DNC guidelines for adults and the 2011 Society of Critical Care Medicine (SCCM), American Academy of Pediatrics (AAP), and Child Neurology Society (CNS) BD/DNC guidelines for children) state that BD/DNC determination requires coma, absence of brainstem reflexes, and the inability to breathe spontaneously during a hypercarbic challenge in a patient with a catastrophic irreversible brain injury.<sup>13,14</sup> As a prerequisite for the BD/DNC evaluation, both guidelines require exclusion of a number of conditions that could falsely suggest a patient meets criteria for BD/DNC including specific mention that there should be no severe metabolic or endocrine disturbances. Neither guideline explicitly requires cessation of hypothalamic neurosecretory function, resulting in controversy about whether there is a mismatch between the UDDA and BD/DNC guidelines.<sup>4,8,12-14</sup>

While some neuroethics experts advocate reconciling this mismatch by interpreting “all functions of the entire brain, including the brainstem” as “the function of the brain as a whole” (i.e., requiring cessation of only certain critical brain functions),

**Figure 1** Concerns With the Uniform Determination of Death Act That Led to a Plan for Revisions<sup>1</sup>

<p style="text-align: center;"><b>Uniform Determination of Death Act</b></p> <p style="text-align: center;">“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 brainstem, is dead. A determination of death must be made in accordance with accepted medical standards.”***</p>
<p style="text-align: center;"><b>Concerns raised by neurologists, health law experts, ethicists, and philosophers</b></p>
<p style="text-align: center;">Should the word “irreversible” be replaced with “permanent”?</p>
<p>What does “the entire brain, including the brainstem” mean? The 2010 AAN and 2011 SCCM/AAP/CNS BD/DNC guidelines do not require cessation of hypothalamic neurosecretory function and both the 2019 AAN BD/DNC position statement and the WBDP acknowledge that hypothalamic neurosecretory function does not preclude BD/DNC determination, but some have argued persistence of hypothalamic neurosecretory function is inconsistent with cessation of all functions of “the entire brain, including the brainstem.”</p>
<p style="text-align: center;">What are the “accepted medical standards”?</p>
<p style="text-align: center;">***Is consent needed prior to BD/DNC evaluation? How should objections to BD/DNC be handled?***</p>

others argue that BD/DNC guidelines should require cessation of every brain function, including hypothalamic neurosecretory function.<sup>4,15</sup> Antidiuretic hormone (ADH) is the most frequently discussed neurosecretory hormone in the context of BD/DNC, but the hypothalamus controls secretion of several other hormones including adrenocorticotropic hormone (ACTH), follicle-stimulating hormone (FSH), growth hormone (GH), luteinizing hormone (LH), oxytocin, prolactin, and thyroid-stimulating hormone (TSH).<sup>16</sup> A review of hypothalamic neurosecretory hormone levels at the time of BD/DNC determination demonstrated normal levels are common: ACTH (48% of 65 patients), ADH (50% of 2,546 patients), and TSH (78% of 347 patients).<sup>16</sup> Both a 2019 AAN position statement on management of objections to BD/DNC determination and the WBDP acknowledge that hypothalamic neurosecretory function does not preclude BD/DNC determination.<sup>11,17</sup>

If the rUDDA stipulates that cessation of hypothalamic neurosecretory function is required for BD/DNC determination, BD/DNC guidelines would need to be revised to comply with the law. This would require identification of a clear clinical process to assess for cessation of hypothalamic neurosecretory function. Questions that would need to be considered include (1) whether levels of all hormones regulated by the hypothalamus would need to be tested; (2) what threshold would be used to determine that there has been cessation of hypothalamic neurosecretory function? and (3) would clinicians be required to provide hormone supplementation after determination of cessation of hypothalamic neurosecretory function, with subsequent documentation of normal levels, before BD/DNC evaluation, to ensure the low levels themselves were not a confounder to the BD/DNC determination? This requirement would complicate and delay completion of the BD/DNC evaluation.

### How Would the rUDDA's Use of the Term Irreversible vs Permanent Affect the Clinical Practice of BD/DNC Determination?

The UDDA uses the term “irreversible” to describe the finality of the cessation of either circulatory and respiratory or brain functions.<sup>12</sup> Irreversible is not defined, but Bernat argues that, in this context, irreversible means “cannot be restored.”<sup>2</sup> This is problematic because there is no requirement to (1) evaluate all patients with cessation of circulatory and respiratory functions for restoration of these functions by cardiopulmonary resuscitation or extracorporeal support (i.e., it is acceptable for patients to have do-not-resuscitate orders) or (2) evaluate all patients with cessation of brain functions for restoration of these functions by medical or surgical interventions to attempt to lower intracranial pressure.<sup>5,9</sup> The WBDP deals with this issue by defining irreversible as “pertaining to a situation or condition that cannot return or resume” and notes that, in the context of BD/DNC determination, “ensuring irreversibility of a person’s clinical state does not require performance of nontherapeutic interventions to decrease intracranial pressure that are not judged to be clinically indicated.”<sup>11</sup>

Bernat argues the term “permanent” is a more appropriate way to describe the cessation of functions required for determination of death and notes that in this context, permanent means “will not be restored because it will neither restart itself...nor will physicians attempt to restart it with resuscitative interventions.”<sup>2</sup> The AAN does not address the distinction between irreversible and permanent in the 2010 BD/DNC guidelines or the 2019 position statement on management of objections to BD/DNC determination.<sup>2,13,17</sup> These documents use the term irreversible, though pose a question about how to ensure cessation of neurologic function is permanent, suggesting the AAN sees these words as interchangeable which, in fact, Bernat<sup>2</sup> says was the way the authors of the UDDA viewed these terms.

The effect of whether the rUDDA uses the term irreversible vs permanent is thus dependent on the definition used. While the UDDA currently uses the term irreversible, it is generally interpreted in clinical practice using the definition provided by the WBDP. If Bernat’s definition of irreversible was operationalized, determination of death would require administration of interventions to prove that function cannot be restored before BD/DNC determination (i.e., hyperosmolar therapy, external ventricular drain placement or decompressive craniectomy) for all patients with catastrophic brain injury, even if this is considered futile. Relatedly, do-not-resuscitate orders would not be permissible for the determination of irreversible cessation of circulatory and respiratory function, and perhaps extracorporeal membrane oxygenation would need to be considered for all patients after cardiac arrest to confirm that the extent of loss of circulatory and respiratory function is irreversible.

### How Would a rUDDA Requirement for Consent Before BD/DNC Evaluation Affect the Clinical Practice of BD/DNC Determination?

Objections to BD/DNC determination, some of which have led to highly publicized lawsuits, prompted the question of whether the UDDA should require consent before BD/DNC evaluation.<sup>6,10,18-21</sup> The BD/DNC evaluation for coma and brainstem areflexia is a more thorough version of routine examinations performed for all patients in the intensive care unit (ICU) with acute brain injury. However, there are potential risks of the apnea test; it could (1) cause cardiopulmonary decompensation or (2) potentially exacerbate brain injury as a result of induced hypercapnia and acidosis.<sup>6</sup> These risks can be minimized by the use of an appropriate technique in accordance with guidelines.<sup>10,13,14</sup> In addition, most clinicians believe that informed consent is not required before BD/DNC evaluation.<sup>20,21</sup> In a 2015 survey of 201 US neurologists in the AAN, 78% of respondents disagreed with the need to obtain consent before BD/DNC evaluation.<sup>20</sup> A survey of pediatric neurologists and intensivists yielded similar results.<sup>21</sup> Although the 2021 AAN Code of Professional Conduct requires informed consent before performance of tests or provision of treatment, this guidance does not apply to BD/DNC evaluation, which, it notes, should be performed in an accurate and timely fashion.<sup>22</sup> Furthermore, the 2019 AAN position statement on management of objections to BD/DNC determination states that clinicians have a professional

obligation to determine death and that, while surrogates should be informed of the intent to perform a BD/DNC evaluation, informed consent is not needed.<sup>17</sup> The WBDP also indicates that there is no need to obtain consent before BD/DNC evaluation.<sup>11</sup> In addition, Nevada and New York issued legal guidance that consent is not required before BD/DNC evaluation.<sup>23,24</sup>

If the rUDDA requires consent before BD/DNC evaluation, the frequency of objections to BD/DNC declaration would likely decrease, although surrogates could give consent for the evaluation and then contest the declaration and discontinuation of organ support. It is unclear how often surrogates would decline to give consent for the evaluation. Half of respondents in the aforementioned surveys encountered a situation in which a family objected to discontinuation of organ support after BD/DNC determination. The true prevalence of objections to BD/DNC determination is unknown, and the available data are not a direct proxy for the frequency at which surrogates would be expected to decline to consent to BD/DNC evaluation.<sup>20,21</sup> It is likely that if surrogates were routinely asked to consent to BD/DNC evaluation, more people would decline than would outright object if they were informed that the evaluation would be performed without explicit request for their permission. Surrogates may consider consenting to BD/DNC evaluation to mean they are giving up on their loved one, but would not object if told a BD/DNC evaluation was the next appropriate step in their care.<sup>25</sup>

If the rUDDA requires consent before BD/DNC evaluation, refusal of consent would necessitate ongoing treatment until the surrogate approved BD/DNC evaluation, cardiac arrest or placement of a tracheostomy and gastrostomy tubes, and transfer to another care location. A patient could exist in this state for months or even years, but they would always be at risk of multiple medical complications and cardiac arrest.<sup>26</sup>

Clinicians would encounter numerous ethical and practical issues if the rUDDA requires consent before BD/DNC evaluation including concerns about futility, moral and psychological distress, management of ICU capacity and resources, and financial considerations regarding remuneration for ongoing treatment of a potentially dead patient.<sup>27</sup> This would undoubtedly have profound implications for patients, surrogates, health care professionals, and society.

## How Does Our Rapidly Evolving Understanding of the Brain's Ability to Recover From Injury Affect the Clinical Practice of BD/DNC Determination?

Some have argued that BD/DNC should not be considered legal death because our rapidly evolving understanding of the

brain's ability to recover from injury precludes the ability to identify irreversible (or permanent) coma, the absence of brainstem reflexes, and the inability to breathe spontaneously during a hypercarbic challenge. Two important examples of our rapidly evolving understanding of the brain's ability to recover from injury include research on (1) disorders of consciousness (DoC) and (2) the ability to restore brain activity after cardiac arrest.

### How Does Our Rapidly Evolving Understanding of DoC Affect the Clinical Practice of BD/DNC Determination?

There is an expanding body of literature that addresses covert consciousness in patients with DoC after acute brain injury.<sup>2,28</sup> The Curing Coma Campaign is establishing new paradigms for the exploration of DoC including characterizing its various endotypes based on structure, function, and both cellular and network activities.<sup>29,30</sup> The campaign aims to improve care and find cures for DoC, and while this is extremely important, it is not relevant to BD/DNC determination because BD/DNC is not classified as a DoC.<sup>13,31</sup> Patients with DoC may be comatose, have an absence of some brainstem reflexes, and require ventilatory support, but they are distinct from patients who meet criteria for BD/DNC. Patients who meet criteria for BD/DNC are comatose, have brainstem areflexia, and are unable to breathe spontaneously during a hypercarbic challenge. In the United States, and much of the world, BD/DNC is conceptualized based on loss of whole-brain function (rather than brainstem or higher brain function).<sup>3,7</sup> As such, patients who meet criteria for BD/DNC are outside the scope of our evolving understanding of DoC.

### How Do Studies on Restoration of Brain Activity After Cardiac Arrest Affect the Clinical Practice of BD/DNC Determination?

Recent studies on restoration of brain activity after cardiac arrest have prompted questions about the potential for recovery of brain function after BD/DNC.<sup>28,30,32-34</sup> Vrselja et al. demonstrated attenuation of cellular death and restoration of cellular metabolism in a pig brain 4 hours after decapitation through the use of a novel pulsatile perfusion system.<sup>32</sup> Abbas et al.<sup>33</sup> reported the ability to measure trans-synaptic neuronal transmission using an electroretinogram in human macular photoreceptors in enucleated eyes.

These findings are groundbreaking and incredibly thought-provoking, but they do not demonstrate reversibility of brain function after BD/DNC determination.<sup>13,14,32,33</sup> Cellular metabolism and photoreceptor responsiveness are not considered clinical functions of the brain for the purposes of BD/DNC determination according to both the UDDA and BD/DNC guidelines.<sup>12-14</sup> In fact, the authors of the UDDA specifically noted that cellular activities of the brain (metabolic, electrical, etc.) are irrelevant to BD/DNC determination unless they forecast recovery of integrated brain function.<sup>12</sup>

## How Do Research Questions About BD/DNC Determination Affect the Clinical Practice of BD/DNC Determination?

It is important to recognize that BD/DNC guidelines are based on consensus opinion of expert knowledge of pathophysiology, clinical experience, and available data.<sup>11,13,14</sup> As such, these guidelines are unique because other guidelines are based on high-quality clinical evidence. There remain many important unanswered questions about BD/DNC (Table 1),<sup>35</sup> and as a result, BD/DNC guidelines are periodically updated to reflect new data and clinical experience. For example, the 2010 AAN BD/DNC guidelines were an update to practice parameters on BD/DNC determination in adults from 1995 and the 2011 SCCM/AAP/CNS BD/DNC guidelines were an update to guidelines on BD/DNC determination in children from 1987.<sup>36,37</sup> These updates were made to facilitate consistency and accuracy in the determination process to avoid false-positive determinations. However, these updates do not represent changes to the fundamental definition of BD/DNC or the process of BD/DNC determination, which remains consistent with the description of BD/DNC published by a Harvard ad hoc committee 50 years ago. The BD/DNC evaluation has always been a clinical assessment for coma, brainstem areflexia, and inability to breathe spontaneously during a hypercarbic challenge.<sup>11,13,14,38</sup>

The authors of the UDDA recognized the potential for health care professionals to update BD/DNC guidelines by using the phrase “accepted medical standards” to identify the way in which death should be determined.<sup>12</sup> However, this incited

controversy in a 2015 lawsuit in which the Supreme Court of Nevada ruled that the identity of the accepted medical standards was unclear.<sup>39</sup> In the rUDDA, the ULC must account for innovation and advancements in medicine while also solidifying the definition of accepted medical standards.<sup>1</sup>

## Are There Special Populations to Consider When Evaluating Controversies Related to the Clinical Practice of BD/DNC Determination?

Two special populations that warrant specific mention when considering controversies related to BD/DNC determination are (1) surrogates who object to BD/DNC determination or discontinuation of organ support after BD/DNC declaration and (2) pediatric patients.

## How Should Clinicians Respond to Objections About BD/DNC Determination or Discontinuation of Organ Support After BD/DNC Declaration?

Half of clinicians involved in BD/DNC determination reported involvement in a situation in which a patient’s surrogate objected to BD/DNC determination or discontinuation of organ support after BD/DNC declaration.<sup>20,21</sup> Despite this, very few states and hospitals have formal legal or institutional processes to manage BD/DNC objections.<sup>40</sup> California, Illinois, and New York require accommodation of BD/DNC objections while New Jersey

**Table 1** Sample of Research Questions About BD/DNC Identified by the World Brain Death Project<sup>35</sup>

Topic	Question
<b>Worldwide variance in BD/DNC</b>	<ul style="list-style-type: none"> <li>• How much variability is there across BD/DNC guidelines within countries?</li> <li>• How does variability in BD/DNC guidelines affect practice and the risk of diagnostic error?</li> </ul>
<b>Concept of BD/DNC</b>	<ul style="list-style-type: none"> <li>• What variables predict temporal evolution to intracranial hypertension and herniation in patients with primary posterior fossa pathology?</li> <li>• Are there tests that can confirm the complete and irreversible destruction of the brainstem?</li> </ul>
<b>Minimum clinical criteria for BD/DNC determination</b>	<ul style="list-style-type: none"> <li>• What is the highest PaCO<sub>2</sub> and lowest pH at which a person has the potential to breathe?</li> <li>• Is neuroimaging evidence of severe intracranial hypertension, including the presence of cerebral edema and central herniation, predictive of, or correlated with a) fulfillment of clinical criteria for BD/DNC, b) absence of spontaneous breathing during apnea testing, and c) absence of brain circulation?</li> </ul>
<b>Beyond minimum clinical criteria for BD/DNC determination</b>	<ul style="list-style-type: none"> <li>• How often, and under what circumstances, does ancillary testing support or contradict a clinical BD/DNC determination?</li> <li>• Does the presence and degree of herniation on neuroimaging correlate with the presence or absence of brain circulation on ancillary testing?</li> <li>• What are the lower limits of brain circulation and duration associated with cessation of brain function?</li> </ul>
<b>Pediatric and neonatal BD/DNC</b>	<ul style="list-style-type: none"> <li>• Is the validity of the PaCO<sub>2</sub> threshold for apnea testing in infants and children the same as in adults?</li> <li>• Can guidelines for pediatric and adult BD/DNC determination be harmonized?</li> </ul>
<b>BD/DNC determination in patients on extracorporeal membrane oxygenation (ECMO)</b>	<ul style="list-style-type: none"> <li>• Does the addition of inhaled carbon dioxide or manipulation of sweep gas flow mitigate the risks of apnea testing in patients on ECMO?</li> </ul>
<b>BD/DNC determination after treatment with targeted temperature management (TTM)</b>	<ul style="list-style-type: none"> <li>• In the presence of neuroimaging evidence of cerebral edema and herniation, what is the minimum time period after rewarming that a clinical determination is reliable?</li> </ul>
<b>Somatic support after BD/DNC</b>	<ul style="list-style-type: none"> <li>• How long can the body continue to function after BD/DNC with provision of somatic support?</li> </ul>

**Table 2** Guidance From the American Academy of Neurology and the World Brain Death Project on Management of Objections to BD/DNC<sup>11,17,22</sup>

Source	Guidance
AAN <sup>17,22</sup>	<ul style="list-style-type: none"><li>• There is a professional obligation to determine death in a timely and accurate manner</li><li>• AAN members should be aware and respectful of BD/DNC laws in the jurisdiction where they practice and should seek expert guidance when addressing BD/DNC objections</li><li>• Surrogates should be notified of the intent to perform a BD/DNC evaluation, but their informed consent is not needed</li><li>• Requests for indefinite accommodation of a BD/DNC objection (continuation of organ support until death by circulatory-respiratory criteria) should be handled by the health care team in conjunction with representatives from hospital administration and legal departments with consideration of involvement of others with mediating skills like clergy members, mental health professionals, or palliative care or ethics consultants</li><li>• There is no ethical obligation to provide medical treatment to a deceased person, and the only state in the United States where indefinite accommodation of a BD/DNC objection is legally required is New Jersey</li><li>• Indefinite accommodation of a BD/DNC objection could be harmful to the patient, family, health care team, and society</li><li>• Transfer of a patient who is believed/known to meet criteria for BD/DNC to another facility should be considered a measure of last resort</li><li>• Hospitals should establish standards that address management of BD/DNC objections</li></ul>
World Brain Death Project <sup>11</sup>	<ul style="list-style-type: none"><li>• Reasonable efforts should be made to notify surrogates of the intent to perform a BD/DNC evaluation, but informed consent is not needed</li><li>• Requests to forego BD/DNC evaluation or continue organ support after BD/DNC should be handled by the health care team in conjunction with representatives from hospital administration and legal departments</li><li>• It is reasonable to continue organ support after BD/DNC for a finite period, assuming the specific time frame is brief and uniform (&lt;48 h); this should be stipulated in a hospital policy</li><li>• Escalation of the existing level of treatment, including cardiopulmonary resuscitation, should not be provided after BD/DNC declaration</li><li>• Utilization of the legal system to resolve controversy in the setting of a BD/DNC objection should be considered a measure of last resort</li><li>• The opinion of a second clinician may help a family accept BD/DNC determination</li><li>• Families should be provided a finite period to seek to arrange transfer of a patient to another facility should they wish to do so before BD/DNC evaluation or discontinuation of organ support after BD/DNC declaration</li><li>• Organ support should be discontinued after BD/DNC declaration if a hospital bed is required for a living patient and no other bed is available</li><li>• Families should be provided with multidisciplinary support and education about BD/DNC</li><li>• Hospitals should establish standards that address management of objections to BD/DNC</li><li>• Health care teams should be trained in cultural sensitivity and communication about BD/DNC</li></ul>

requires determination of death by circulatory-respiratory criteria if a surrogate indicates that a patient has a religious or moral BD/DNC objection.<sup>20,21,39</sup> No other states have legal guidance addressing BD/DNC objections. Both the AAN and the WBDP provide practical guidance about management of BD/DNC objections (Table 2).<sup>11,17,22</sup> Clinician responses to BD/DNC objections vary in both accommodation and nonaccommodation states, but discontinuation of organ support after BD/DNC declaration over surrogate objection is rare, in large part because of the fear of litigation or media coverage.<sup>20,21</sup> Although the rUDDA could be a means to facilitate consistent legal guidance across states about how to address these objections, the ideal approach is unclear (Figure 2).<sup>27</sup> In the meantime, clinicians should (1) formulate hospital policies that address management of BD/DNC objections and (2) seek support and guidance from hospital administration and legal counsel if they encounter a surrogate who objects to a BD/DNC evaluation or discontinuation of organ support after BD/DNC declaration.

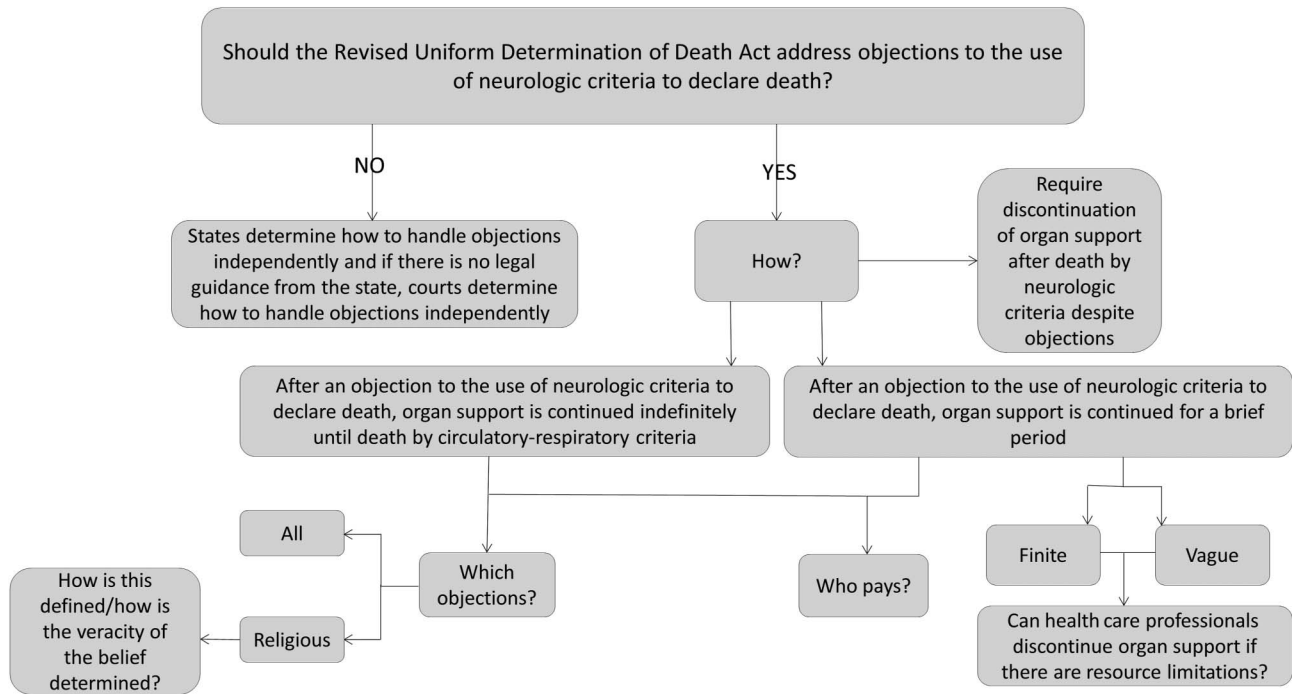
### How Do Contemporary Controversies Related to BD/DNC Affect the Clinical Practice of BD/DNC Determination in Pediatrics?

Survey data suggest that surrogates of pediatric patients may object to BD/DNC more often than those of adult patients (61% of pediatricians vs 48% of adult neurologists reported that they had encountered an objection to BD/DNC determination or discontinuation or organ support after BD/DNC).<sup>20,21</sup> In the 2015 AAN member survey on management of BD/DNC objections, 32% of adult neurologists indicated they believed that objections should be handled differently for

pediatric and adult patients.<sup>20</sup> If the ULC chooses to address BD/DNC objections in the rUDDA, they will need to decide whether objections from surrogates of pediatric patients should be handled differently from those of adults.<sup>27</sup>

There are also unique considerations related to the BD/DNC determination process in pediatric patients. Although the fundamental tenets of BD/DNC determination are the same for children and adults, the 2011 SCCM/AAP/CNS BD/DNC guidelines are not identical to the 2010 AAN guidelines.<sup>13,14,41</sup> Some of these differences seem arbitrary. For example, the 2011 SCCM/AAP/CNS guidelines require a minimum temperature of >35°C, whereas the 2010 AAN guidelines require a minimum temperature of >36°C. However, other differences suggest a higher degree of conservatism for BD/DNC determination for children. The adult guidelines require only one examination and apnea test, but the pediatric guidelines require 2 independent examinations and apnea tests with an age-dependent interexamination observation period. The WBDP also suggests the minimum standard for BD/DNC determination is a single examination/apnea test in adults and 2 examinations/apnea tests in children.<sup>11</sup> These different requirements are based in part on the fact that the pathophysiologic response to acute brain injury may be different in children and especially in infants, particularly in response to hypoxic-ischemic injury. Both the AAN and the WBDP have posed the question of whether guidelines for pediatric and adult BD/DNC determination can be harmonized into a single standard while accounting for physiologic and anatomical differences.<sup>35,42</sup>

**Figure 2** Flow Diagram for Consideration of the Question: “Should the Revised Uniform Determination of Death Act Address Objections to the Use of Neurologic Criteria to Declare Death?”



Reprinted with permission from Lewis A. Should the revised Uniform Determination of Death Act address objections to the use of neurologic criteria to declare death? *Neurocrit Care* 2022; 37 (2): 377-85.<sup>27</sup>

## How Has the AAN Addressed Potential Threats and Impediments to the Clinical Practice of BD/DNC Determination?

The AAN includes over 30,000 members from the United States, and at least one-third have the potential to be involved in BD/DNC determination.<sup>43</sup> The AAN’s vision is to be “indispensable” to members, and its mission is to “promote the highest quality patient-centered neurologic care and enhance member satisfaction.” The AAN’s values include respect for the dignity and uniqueness of each person; professionalism; integrity; community; leadership; and inclusion, diversity, equity, antiracism, and social justice. With this mission and values in mind, the AAN has taken numerous steps to address controversies related to BD/DNC (Figure 3) through the development of practice resources, solicitation of member feedback, conferences, education, and advocacy.<sup>13,17,20,22,36,42-44</sup>

### Development of Practice Resources on BD/DNC Determination

In 1995, the AAN noted (1) BD/DNC determination is not easy, (2) a perceived need for standardizing the evaluation, (3) variability in practice, (4) a controversy regarding the utilization of ancillary tests, and (5) government and third-party payers

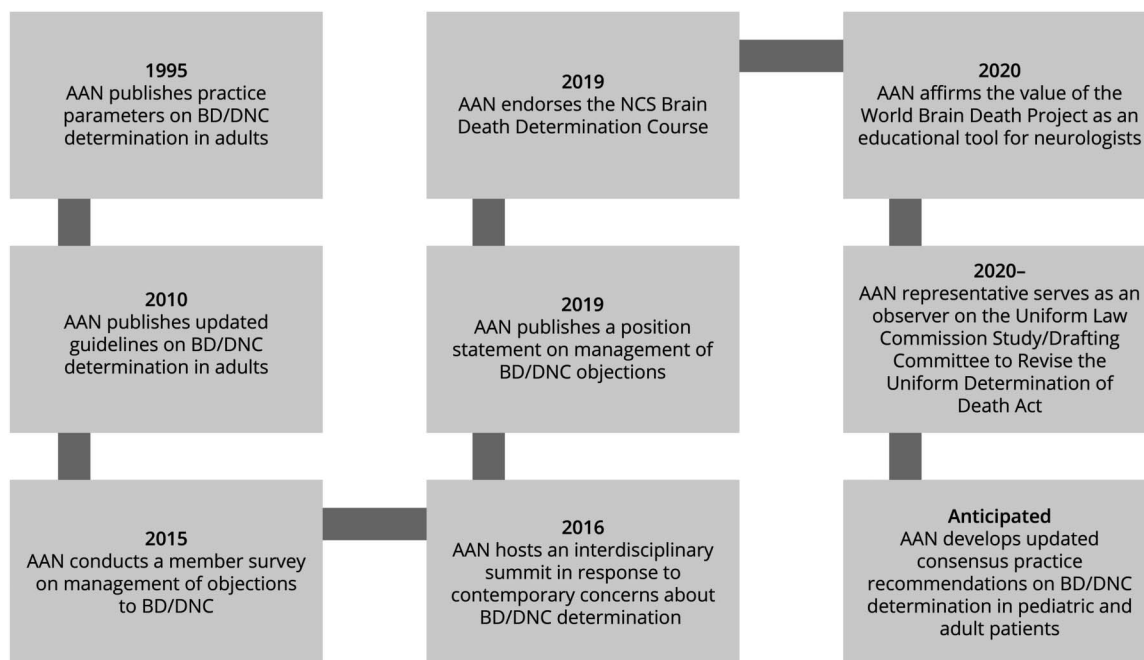
needed a well-defined practice parameter on determination of BD/DNC.<sup>36</sup> To address these issues, the AAN published practice parameters on BD/DNC determination in adults. In 2010, the AAN updated these guidelines in response to variability across hospital BD/DNC determination policies and deficiencies in documentation.<sup>13</sup>

Although most AAN members care for adult patients, the AAN also includes pediatric neurologists. Accordingly, along with the AAP, American Neurological Association (ANA), and CNS, the AAN endorsed the 1987 guidelines for BD/DNC determination in children published by the Task Force for BD/DNC determination in Children.<sup>37</sup> The AAN subsequently affirmed the value of the 2011 SCCM/AAP/CNS updated guidelines for BD/DNC determination in children. At present, the AAN is actively collaborating with adult and pediatric BD/DNC experts to develop a singular consensus practice guideline on BD/DNC determination in persons of all ages.<sup>43</sup>

### Solicitation of Member Feedback on BD/DNC Objections

In 2015, in response to member concerns about BD/DNC objections, the AAN assessed members’ experience with BD/DNC objections, perspectives on management of BD/DNC objections, and institutional resources to address BD/DNC objections.<sup>20</sup> Members requested that the AAN advocate for codification of legislation about BD/DNC objections to both

**Figure 3** Time Line of Steps the American Academy of Neurology Has Taken to Address Controversies Related to BD/DNC<sup>13,17,20,22,36,42,44</sup>



guide and protect physicians; clear policies about management of objections; and improvements in education about BD/DNC for physicians, families, and the public at large.

### Conferences Related to BD/DNC

In response to both this feedback and a surge in lawsuits related to BD/DNC determination, the AAN organized an interdisciplinary quality improvement summit in 2016.<sup>42</sup> Attendees included adult and pediatric neurologists, intensivists, an anesthesiologist, a neuroradiologist, ethicists, and lawyers. The group identified 5 goals: (1) to develop and promote educational initiatives on BD/DNC determination for members of the health care community, legal community, and the public in the United States; (2) to promote BD/DNC training and credentialing programs for clinicians involved in BD/DNC determination; (3) to advocate for uniform hospital policies on BD/DNC determination through implementation of regulatory oversight; (4) to advocate for a consistent legal approach to BD/DNC throughout the country; and (5) to develop a singular standard for BD/DNC determination for persons of all ages. A statement summarizing the summit was endorsed by the AAN, AAP, the American College of Chest Physicians, the American College of Radiology, ANA, the American Society of Neuroradiology, and the Child Neurology Society. The Neurocritical Care Society (NCS) endorsed the statement as an educational tool on the topic of BD/DNC determination.

### Development of Practice Resources on Management of BD/DNC Objections

Based on both member feedback and the discussion at the summit, the AAN published a position statement in 2019 on

management of BD/DNC objections.<sup>17,20,42</sup> It emphasizes that the AAN's positions were developed based on the goal to "obtain, maintain, and bolster public trust," in consideration of the mission to promote the highest quality patient-centered neurologic care and the vision to be indispensable to its members.<sup>17</sup> The 2021 AAN Code of Professional Conduct also affirms the importance of completing BD/DNC evaluations in an accurate and timely fashion.<sup>22</sup> Table 2 summarizes the AAN's guidance in these practice resources on management of BD/DNC objections.

### Education on BD/DNC

To develop and promote educational initiatives on BD/DNC, the AAN organizes a didactic session and workshop related to BD/DNC at the Annual Meeting and has created a NeuroBytes case series for medical students on BD/DNC determination.<sup>43</sup> In addition, the AAN has supported other organizations' work to facilitate BD/DNC education including endorsing the NCS BD/DNC Determination Course, which was designed to standardize the process of BD/DNC determination and provide certification, which could potentially be used for credentialing in the future.<sup>44</sup> The AAN also affirmed the value of the WBDP as an educational tool for neurologists.<sup>11</sup>

### Advocacy to Address Legal Controversies Related to BD/DNC

The AAN supported the need for revisions to the UDDA to promote a consistent legal approach to BD/DNC throughout the country and appointed a representative to serve as an observer on the drafting committee of the ULC.<sup>1,18</sup> This ensures that the AAN (1) can educate the commissioners who will



ultimately make the decision about how to revise the UDDA and (2) has a voice in the revision process.<sup>1</sup>

## The Future of the Clinical Practice of BD/DNC Determination

Ideally, BD/DNC determination should be just as uncontroversial as determination of a diagnosis of stroke, Guillain-Barré syndrome, radiculopathy, or any other neurologic condition. However, there are, and always will be, varying philosophical, social, and religious perspectives about death, creating the potential for controversy which can affect the clinical practice of BD/DNC determination.<sup>2,11,28</sup>

### How Should the AAN Position Itself on Controversies Related to BD/DNC?

It is clear that the AAN and numerous other national and global medical societies, including the World Federation of Neurology, support the concept that BD/DNC is legal death.<sup>11</sup> Going forward, in accordance with its mission, vision, goals, and values, the AAN should continue to strive to minimize controversy related to BD/DNC.<sup>43</sup> This requires ongoing collaboration with other stakeholder organizations to promote a consistent approach to BD/DNC determination throughout the United States and leadership to facilitate education about BD/DNC to members, the general health care community, and the public. These steps will help ensure public trust in clinicians' ability to accurately and consistently declare death.

Furthermore, the AAN must continue to identify and mitigate potential threats and impediments to the clinical practice of BD/DNC determination by considering the perspectives of patients, surrogates, health care professionals, and society. This requires recognition that addressing BD/DNC objections is challenging for bedside clinicians because of competing ethical and practical priorities. The AAN must also advocate for a consistent legal approach to BD/DNC determination and management of BD/DNC objections across all states.<sup>20,27,42</sup>

### What Would the Optimal UDDA Revision Look Like and What Would Its Implications Be on the Clinical Practice of BD/DNC Determination?

The ULC has numerous decisions to make about how to revise the UDDA.<sup>1,27</sup> There is no single "best way" to revise the UDDA, and even with the best of intentions, any revisions have the potential to lead to further controversy.<sup>2</sup> It is important to recognize that the rUDDA will only be a recommended statute. Every state will have the opportunity to decide whether to adopt or amend the rUDDA. In the end, there may still be state-by-state variability in statutes for death determination and management of BD/DNC objections.<sup>1</sup>

In the best-case scenario, the rUDDA has the potential to improve consistency and accuracy of BD/DNC determination and decrease controversies related to BD/DNC.<sup>1</sup> However, in

addition to the work of the ULC, ongoing efforts are needed to facilitate credentialing of clinicians involved in BD/DNC determination and regulation of hospital BD/DNC policies to ensure they are consistent with national standards on BD/DNC determination.<sup>42</sup> These combined efforts will ideally minimize controversies, lawsuits, and potential threats and impediments to the clinical practice of BD/DNC determination.

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## Potential Threats and Impediments to the Clinical Practice of Brain Death Determination: The UDDA Revision Series

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