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NOTES

VALUING THE VOICELESS: A PATH FORWARD FOR DETERMINING BRAIN DEATH WITHOUT JEOPARDIZING THE RIGHT TO LIFE OF VULNERABLE PATIENTS IN INDIANA

AMY GAISSER*

INTRODUCTION

> The more I thought about Juan, the more I realized how little we still understood about consciousness and its many faces. We'd thrown everything we had at Juan, every type of brain scan, every newfangled technique we had at our disposal; yet we had failed to spot consciousness where consciousness clearly existed . . . .
>
> —Adrian Owen[1]

It was just like any other ordinary Friday. Juan, then nineteen years old, had enjoyed an evening out with friends.[2] When he got home, he had a quick bite to eat, said goodnight to his parents, and went to bed.[3] By morning, he was completely unresponsive.[4]

Juan was rushed to the hospital, where physicians found that he had "extensive damage to the white matter in his brain, including the frontal and parietal lobes, regions critical for working memory, attention, and other high-level cognitive functions."[5] He was rated a 3 on the Glasgow Coma Scale, which is the lowest score possible before being considered dead.[6] Despite the use of

* J.D. Candidate, 2026, Indiana University Robert H. McKinney School of Law; B.S. 2013 and M.S. 2015, Butler University. Recipient of the Papke Prize for Best Student Note in Volume 59, endowed by and named in honor of David R. Papke, former R. Bruce Townsend Professor of Law and faculty advisor to the *Indiana Law Review*. I dedicate this Note in loving memory of my parents, John and Cynthia Gaisser, and I express my sincere gratitude to Professor John L. Hill, Shelby Mohr, Adam Destrampe, Meredith Fulton, and my Volume 59 *Indiana Law Review* colleagues for their feedback and encouragement.

1. ADRIAN OWEN, INTO THE GRAY ZONE 215 (2017).
2. *Id.* at 207.
3. *Id.*
4. *Id.*
5. *Id.*
6. *Id.* at 208.

cutting-edge fMRI technology to test for any signs of consciousness in Juan, neuroscientist Adrian Owen and his colleagues came up empty-handed.[7]

Seven months later, to everyone's surprise, Juan was no longer vegetative: he was eating, walking, and talking again.[8] A year later, he was attending school.[9] "The doctors [had] said his brain was done. Zero chance of recovery and no options," his mother recalled.[10] Reflecting on that experience, she said to Owen, "We were at a very dark point in our lives . . . . You gave us hope."[11]

In 2022, a similar situation occurred right here in Indianapolis, Indiana.[12] A seventeen-year-old girl named Treasure Perry had a severe allergic reaction at work.[13] She was taken to the Riley Hospital for Children where, days later, she was pronounced brain dead.[14] In this case, however, her mother met resistance, not hope. Despite observing signs of life in Treasure and expressing that the removal of Treasure's life support would "go[] against [her] beliefs,"[15] Treasure's mother could do nothing but watch helplessly when the Marion Superior Court ordered that "all medical treatment, including mechanical ventilation, be discontinued."[16]

The legal basis for this order came from Indiana Code § 1-1-4-3,[17] in which Indiana has adopted, word-for-word, the language of the Uniform Determination of Death Act (UDDA).[18] The UDDA defines brain death as the "irreversible cessation of all functions of the entire brain, including the brain stem."[19] The UDDA also indicates that brain death must be determined "in accordance with accepted medical standards."[20] Nonetheless, the current accepted medical standards are implemented inconsistently[21] and do not measure all functions of the brain or brain stem.[22] Consequently, brain death is frequently determined while some functions of a patient's brain are, or may still

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7. *Id.*

8. *Id.* at 209.

9. *Id.* at 216.

10. *Id.* at 216–17.

11. *Id.* at 216.

12. Erik Ortiz, *Her daughter was declared dead. Despite hospital objections, she believes she was alive.*, NBC NEWS (Aug. 11, 2022, 15:01 ET), https://www.nbcnews.com/news/us-news/daughter-was-declared-dead-hospital-objections-%20believes-alive-rcna42612 [https://perma.cc/V684-F2TU].

13. *Id.*

14. *Id.*

15. *Id.*

16. *In re* Perry, No. 49D06-2208-MI-026530, at 5 (Ind. Super. Ct. Marion Cnty. Aug. 11, 2022).

17. Uniform Determination of Death Act, IND. CODE § 1-1-4-3 (2025).

18. Uniform Determination of Death Act § 1 (1980).

19. *Id.*

20. *Id.*

21. Alexandra Junn & David Y. Hwang, *Practice Variability in Determination of Death by Neurologic Criteria for Adult Patients*, YALE J. BIOLOGY & MED. 719, 721 (2019).

22. Michael Shapiro, *Euthanasia by Organ Donation*, 41 DALHOUSIE L.J. 153, 161 (2018).

be, active.[23] False positive determinations of brain death also occur with regularity, due to inaccurate implementation of the standards.[24]

Furthermore, even if it were possible to ensure that "every neuron in the brain ha[d] ceased functioning,"[25] a problem remains: patients who are considered brain dead from a legal standpoint are often still biologically alive.[26] In other words, patients whose bodies are still pumping blood, still fighting infections, and still functioning in any other way are still alive.[27]

Brain death, in fact, is a legal fiction, meaning that the law treats brain death as equivalent to biological death for practical purposes.[28] In large part, this is due to the need for more organ donations, since organs are "severely [in] short supply."[29] The challenge, however, is that vital organs like the heart cannot be harvested from living patients for two reasons. First, physicians take the Hippocratic Oath to "do no harm."[30] Second, the "dead donor rule" (DDR) prohibits the removal of "any vital organs" before a patient has died.[31] Thus, it is often necessary, legally, for a patient to be declared brain dead before their surrogates can consent to organ donation.[32] In reality, though, as Michael Shapiro explains in *Euthanasia by Organ Donation*, "[i]t is the discontinuation of artificial respiration [prior to the harvesting of organs] that results in the death of the patient at the time they die, rather than the disease process."[33]

When voiceless patients die by the removal of life support, without an advance directive or approval from their surrogate(s), it is a violation of their right to life under the Fourteenth Amendment.[34] Additionally, when providers justify withdrawing life support by promoting brain death as a biological truth,[35] and then use the DDR as a façade to avoid the reality that the patient is still alive,[36] this lack of transparency invalidates surrogates' informed consent to

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23. Michael Nair-Collins & Franklin G. Miller, *False Positives in the Diagnosis of Brain Death*, 28 CAMBRIDGE Q. OF HEALTHCARE ETHICS 648, 648 (2019).

24. *Id.*

25. Rob Stein, *Debate simmers over when doctors should declare brain death*, NAT'L PUB. RADIO (Feb. 11, 2024, 7:01 ET), https://www.npr.org/sections/health-shots/2024/02/11/1228330149/brain-death-definition [https://perma.cc/4VVH-7FGD].

26. Seema K. Shah, *Piercing the Veil: The Limits of Brain Death as a Legal Fiction*, 48 U. MICH J.L. REFORM 301, 302 (2015).

27. *Id.*; Katherine Schiller, *Life After Brain Death*, 41 J. LEGAL MED. 205, 206 (2021).

28. Shah, *supra* note 26, at 304.

29. Stein, *supra* note 25.

30. Schiller, *supra* note 27, at 207.

31. *Id.* at 206.

32. Shah, *supra* note 26, at 315.

33. Shapiro, *supra* note 22, at 165.

34. U.S. CONST. amend. XIV, § 1.

35. Nair-Collins & Miller, *supra* note 23, at 648.

36. *See* Robert D. Truog, *Defining Death: Getting It Wrong for All the Right Reasons*, 93 TEX. L. REV. 1885, 1899 (2015) ("[D]ependence upon life support cannot be a reason for considering a person to be dead.").

their loved ones' organ donations.[37] To validate consent, the legal fiction must be acknowledged.

Moreover, a recently suggested revision to the UDDA—namely, that the adjective describing "cessation" be changed from "irreversible" to "permanent"[38]—poses grave concerns for patients from vulnerable populations that tend to be devalued by society.[39] This is because "permanent" is a lower standard of brain death to meet, permitting death to be declared when a provider or surrogate *chooses* to stop medical interventions.[40] Thus, this one-word revision would allow for the legally permissible euthanasia of multiple groups of voiceless but living patients, including patients like Juan, based on others' value judgments about their lives.[41]

Not only are these issues surrounding brain death likely to cause emotional distress for patients' family members, but they also violate the First Amendment's Free Exercise Clause by substantially hindering patients' and families' ability to exercise their religious beliefs in life-or-death health care situations.[42] Only one state, New Jersey, offers a complete religious exemption from brain death for individuals who believe solely in cardiac death.[43] Indiana offers no exemption, as Treasure's family experienced firsthand, and that needs to change.[44]

Accordingly, this Note argues for a wholistic revision of brain death within Indiana's UDDA to safeguard the right to life of vulnerable patients in Indiana. It also calls for increased transparency about the biological reality of brain death to give validity to patients' and surrogates' informed consent for organ donations. To these ends, Part I of this Note discusses the ideologies underlying the UDDA by giving an overview of its evolution over time. Part II delves into the legal, medical, religious, and social factors that matter most when determining how to revise the UDDA. Part III argues that a comprehensive revision of brain death within Indiana's UDDA—including a complete exemption from brain death, the continued use of "irreversible," heightened and standardized medical standards, and a requirement of transparency for informed consent—is not only a constitutional necessity but also in the best interests of patients. By raising the bar for the determination of brain death moving forward, Indiana could lead the way in ensuring that the lives of vulnerable, voiceless patients are not unconstitutionally taken.

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37. IND. CODE § 34-18-12-3 (2025).

38. DETERMINATION OF DEATH ACT § 3 (UNIF. L. COMM'N, Draft June 27, 2023).

39. Schiller, *supra* note 27, at 212.

40. Jennifer Popik, *Comments: National Right to Life Committee, Inc.*, UNIF. L. COMM'N (July 11, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

41. Schiller, *supra* note 27, at 212.

42. U.S. CONST. amend. I.

43. New Jersey Declaration of Death Act, N.J. REV. STAT. § 26:6A-5 (2025).

44. Uniform Determination of Death Act, IND. CODE § 1-1-4-3 (2025).

I. IDEOLOGIES UNDERLYING THE UNIFORM DETERMINATION OF DEATH ACT

A. Death: An Evolving Concept

It turns out that death is not as final as it seems; it is a concept that continues to evolve. In the not-so-distant past, death was only determined when a patient's breathing and heartbeat had stopped (i.e., cardiac death).[45] In the mid-1900s, however, two major medical advances led to the need to reconceptualize what death meant: one was the modern ventilator;[46] the other was the first successful heart transplant.[47]

The dawn of the modern ventilator made it possible for patients who would otherwise have died to live on for years by means of mechanical ventilation.[48] Some viewed this invention as simply "masking" a death that had already occurred; others saw it as a life-saving piece of technology, akin to a pacemaker or dialysis.[49] In addition to these differing viewpoints, there was also a concern that patients who remained on a ventilator for years would burden their families and the health care system.[50] Furthermore, there were ethical questions: Did these patients want to be kept alive?[51] *Should* they be kept alive?[52]

Secondly, there was the new prospect of organ transplantations. This possibility, like the modern ventilator, was controversial.[53] For instance, would the donor be dead prior to, or die from, the transplant?[54] How could illegal

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45. Thaddeus Mason Pope, *Brain Death Forsaken: Growing Conflict and New Legal Challenges*, 37 J. LEGAL MED. 265, 270 (2017) (citing James L. Bernat, *The Definition and Criterion of Death*, 118 HANDBOOK OF CLINICAL NEUROLOGY 419, 419–20 (2013)).

46. Bob Marcotte, *Ventilators: Three Centuries in the Making*, U. ROCHESTER (Apr. 11, 2020), https://www.rochester.edu/newscenter/brief-history-of-ventilators-424312 [https://perma.cc/R2XP-VPZ6].

47. *First Heart Transplant Performed Thirty-Five Years Ago*, ORGAN PROCUREMENT & TRANSPLANTATION NETWORK (Dec. 3, 2002), https://optn.transplant.hrsa.gov/news/first-heart-transplant-performed-35-years-ago [https://perma.cc/9RWR-TDRX] (performed by Christiaan Barnard in Cape Town, South Africa).

48. Shapiro, *supra* note 22, at 165.

49. Shah, *supra* note 26, at 312.

50. Henry K. Beecher et al., *A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 JAMA 337, 337–40 (1968).

51. Alvin Powell, *Death Is Universal, but Sometimes Murky*, HARV. GAZETTE (July 24, 2018), https://news.harvard.edu/gazette/story/2018/07/harvard-ethicist-robert-truog-on-why-brain-death-remains-controversial [https://perma.cc/TQ9H-ANBV].

52. *Id.*

53. Scott J. Schweikart, *Reexamining the Flawed Legal Basis of the "Dead Donor Rule" as a Foundation for Organ Donation Policy*, 22 AMA J. ETHICS 1019, 1020 (2020).

54. Truog, *supra* note 36, at 1887.

harvesting be prevented to protect patients from exploitation?[55] Would transplant surgeons be held liable for the deaths of organ donors?[56]

As a result of these two medical advances and the concerns they posed, Henry Beecher, an anesthesiologist from Harvard Medical School, called for the formation of an Ad Hoc Committee of his colleagues to consider developing a definition of brain death.[57] This committee included medical professionals, researchers, and professors of various areas of expertise.[58] After much deliberation, the Committee suggested a new possible diagnosis—"irreversible coma"—which focused on a loss of neurological functioning in patients.[59]

According to the Committee, the criteria for determining "irreversible coma" would be threefold: (1) "unreceptivity or unresponsivity" to stimuli (meaning no response to pain), (2) "no movements or breathing" (tested by watching for breathing after discontinuation of a ventilator), and (3) "no reflexes" (meaning no pupil dilation, blinking, yawning, swallowing, etc.).[60] Furthermore, all of these criteria would be assessed "by purely clinical signs," meaning by observation alone.[61] The Committee did not mandate medical testing, such as the use of an electroencephalogram (EEG);[62] it only *recommended* an EEG.[63] A flat EEG would be considered indicative of "irreversible coma."[64] The Committee also cautioned against the possibility of false diagnoses, which could occur in patients with hypothermia (a dangerously low body temperature) or after giving medications that depress the central nervous system.[65]

While the Committee felt confident that these criteria could diagnose irreversible unconsciousness, they remained hesitant to suggest that this should become a new definition of death.[66] Prominent bioethicist and pediatrician Robert Truog, currently a professor at Harvard Medical School and Boston Children's Hospital,[67] would have supported that hesitancy, as he believes that the Committee failed to provide "any scientific, philosophical, or logical

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55. *See* Norbert W. Paul et al., *Cases Abusing Brain Death Definition in Organ Procurement in China*, 31 CAMBRIDGE Q. OF HEALTHCARE ETHICS 379, 381–82 (2022).

56. Schweikart, *supra* note 53, at 1019.

57. Beecher et al., *supra* note 50, at 337.

58. Ariane Lewis et al., *Shouldn't Dead Be Dead?: The Search for a Uniform Definition of Death*, 45 J.L. MED. & ETHICS 112, 112 (2017).

59. Powell, *supra* note 51.

60. Beecher et al., *supra* note 50, at 337–38.

61. *Id.* at 337.

62. *Electroencephalogram (EEG)*, JOHNS HOPKINS MED., https://www.hopkinsmedicine.org/health/treatment-tests-and-therapies/electroencephalogram-eeg [https://perma.cc/RF39-D22A] (last visited Jan. 18, 2025) (describing an EEG as a test where electrodes are placed on a patient's scalp to detect the electrical activity of that patient's brain).

63. Beecher et al., *supra* note 50, at 338.

64. *Id.*

65. *Id.*

66. Powell, *supra* note 51.

67. *Robert D. Truog, MD, MA: Bio*, HARV. MED. SCH., https://bioethics.hms.harvard.edu/faculty-staff/robert-d-truog [https://perma.cc/HG5J-GVPS] (last visited Jan. 16, 2025).

justification for why the state of irreversible coma could be equated with death."[68]

Nonetheless, Kansas proceeded to adopt the Harvard criteria into law, and several other states followed.[69] This meant that a patient could be simultaneously alive in one state while dead in another, leading to complications with inheritance, taxation, and other areas of the law.[70] Therefore, President Carter called for a special commission to address these inconsistencies.[71]

The Commission began by identifying issues with the Harvard criteria, including (1) the inability to test for "unreceptivity"—the complete unawareness of stimuli[72]—in an unconscious patient and (2) the misleading use of the word "coma," which refers to "a condition of a *living* person."[73] The word "coma" was, thus, removed from the definition, and a model statute, keeping the adjective of "irreversible," was proposed.[74]

That model statute, now known nationwide as the Uniform Determination of Death Act (UDDA), allowed for the determination of death in either of the following two ways:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions [cardiac death], or (2) irreversible cessation of all functions of the entire brain, including the brain stem [brain death], is dead. A determination of death must be made in accordance with accepted medical standards.[75]

The UDDA intentionally left "accepted medical standards" undefined to allow physicians and other specialists to adjust their methods for determining death in response to future advances.[76]

In the late 1990s, around fifteen years after the UDDA's creation, research emerged that questioned the validity of brain death.[77] Most notably, that research came from Dr. D. Alan Shewmon, a pediatric neurologist with triple board certification in Pediatrics, Neurology, and Electroencephalography who is now retired from serving as Professor of Neurology and Pediatrics at UCLA's School of Medicine and as Chief of the Neurology Department at Olive-UCLA

68. Truog, *supra* note 36, at 1887–88.

69. PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMEDICAL & BEHAV. RSCH., DEFINING DEATH: A REPORT ON THE MEDICAL, LEGAL, AND ETHICAL ISSUES IN THE DETERMINATION OF DEATH 62 (1981) [hereinafter PRESIDENT'S COMM'N].

70. Lewis et al., *supra* note 58, at 113.

71. PRESIDENT'S COMM'N, *supra* note 69, at 6.

72. Beecher et al., *supra* note 50, at 337.

73. PRESIDENT'S COMM'N, *supra* note 69, at 25 (emphasis added).

74. *Id.* at 73.

75. Uniform Determination of Death Act § 1 (1980).

76. Ariane Lewis et al., *Determination of Death by Neurologic Criteria in the United States: The Case for Revising the Uniform Determination of Death Act*, 47 J.L. MED. & ETHICS 9, 13 (2019).

77. Shah, *supra* note 26, at 313.

Medical Center.[78] Dr. Shewmon successfully showed that some patients, who had been accurately determined to be dead under neurological criteria, could perform integrative bodily functions, including wound healing, maintaining a warm body temperature, mounting stress responses to pain, and fighting infections.[79] Many of the patients determined to be brain dead also still had a functioning hypothalamus[80]—which is a "coordinating center" that stabilizes the body's temperature, blood pressure, hunger, thirst, sleep, and more[81]—and some patients even underwent puberty or gestated fetuses.[82] This significantly undermined the assertion that these patients were, in fact, biologically dead.[83]

In response to this research, President George W. Bush gathered a group of scholars in 2008 to determine whether to abandon brain death altogether or develop a new rationale for why "brain dead" patients should be considered dead.[84] This group was called the President's Council, and it opted for the second option: creating a new rationale.[85] It noted that completely abandoning the concept of brain death would greatly hinder organ transplantations due to the "dead donor rule" (DDR).[86] The DDR is not a legal construct, but it is a widely held belief among physicians that "it is wrong to kill one person to save the life of another."[87] This means that the organ donor "must already be dead before vital organs are removed."[88] Since patients determined to be brain dead are the "ideal source of transplantable organs," keeping the neurological criteria for death was crucial for the continuance of life-saving transplantations.[89]

With this consideration in mind, the President's Council introduced the idea of "total brain failure," also known as the "whole brain" standard.[90] The Council defined this failure as a cessation of the "fundamental vital *work* of a living organism," which it viewed as receptivity to external stimuli, the ability to act upon the world to meet one's needs, and the "basic felt need" that drives a person to act.[91] For diagnostic purposes, the Council said that "total brain failure" has

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78. Declaration of D. Alan Shewmon, M.D. at 1, McMath v. California, No. 15-CV-06042-HSG (N.D. Cal. Dec. 12, 2016).

79. D. Alan Shewmon, *The Brain and Somatic Integration: Insights Into the Standard Biological Rationale for Equating "Brain Death" with Death*, 26 J. MED. & PHIL. 457, 467–68.

80. Shah, *supra* note 26, at 311.

81. *Hypothalamus*, CLEV. CLINIC (Mar. 16, 2022), https://my.clevelandclinic.org/health/body/22566-hypothalamus [https://perma.cc/2WQ7-URRE].

82. Shewmon, *supra* note 79, at 468–69.

83. Shah, *supra* note 26, at 312.

84. PRESIDENT'S COUNCIL ON BIOETHICS, CONTROVERSIES IN THE DETERMINATION OF DEATH: A WHITE PAPER BY THE PRESIDENT'S COUNCIL ON BIOETHICS 6, 11 (2008).

85. *Id.* at 58.

86. *Id.* at 10–12.

87. Ann Thorac Surg, *Consequences of the Dead Donor Rule*, NAT'L LIBR. OF MED., at 5 (Apr. 2014), https://pmc.ncbi.nlm.nih.gov/articles/PMC4100619 [https://perma.cc/9YZC-VA22].

88. *Id.*

89. PRESIDENT'S COUNCIL ON BIOETHICS, *supra* note 84, at 8.

90. *Id.* at 19.

91. *Id.* at 60–61.

occurred when the following criteria are met: (1) a documented history of injury rather than a transient cause of current symptoms, (2) complete unresponsiveness, (3) no brainstem reflexes, and (4) no drive to breathe during an apnea test.[92] This was strikingly reminiscent of the Harvard criteria from 1968, forty years prior.[93]

While acknowledging that uncertainties about the validity of brain death determinations should be worked out first "on [their] own terms," without "an eye to the practical effects that a new standard for determining death might have," the Council nonetheless proceeded to consider organ donorship at the forefront of its discussions, ultimately concluding that brain death was "conceptually sound."[94] As Dr. Shewmon has said, "At its inception, 'brain death' was proposed not as a coherent concept but as a *useful* one"—in other words, as a means to an end.[95]

Due to lawsuits and lingering questions, the American Academy of Neurology (AAN) was concerned about losing the public's trust in the legitimacy of brain death.[96] For example, conditions like Guillain-Barré syndrome[97] and high cervical spine injury[98] "mimic brain death," thus leading to false positive determinations of brain death in patients.[99] Therefore, in 2016, the AAN convened an interdisciplinary summit, called the Quality Standards Subcommittee, to address these issues.[100] The Subcommittee explicitly discussed the shortfalls of assessing brainstem reflexes clinically, such as the inability of patients with a cervical spine injury to demonstrate spinal reflexes, facial trauma that could mask a patient's facial responses, and the effects that neuromuscular blocking agents and other drugs could have on patients' ability to move in response to stimuli.[101] Notwithstanding these issues, the AAN still decided that confirmatory tests, such as EEGs, should remain optional when determining brain death.[102]

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92. *Id.* at 33–34.

93. Beecher et al., *supra* note 50, at 337–38.

94. PRESIDENT'S COUNCIL ON BIOETHICS, *supra* note 84, at 9–12.

95. D. Alan Shewmon, *Brain Death: A Conclusion in Search of a Justification*, HASTINGS CTR. REP. S22, S22 (2018) (emphasis added).

96. Lewis et al., *supra* note 76, at 9.

97. *Guillain-Barré Syndrome*, JOHNS HOPKINS MED., https://www.hopkinsmedicine.org/health/conditions-and-diseases/guillainbarr-syndrome [https://perma.cc/NLU2-N3R7] (last visited Jan. 18, 2025) (describing Guillain-Barré syndrome as a neurological disorder "in which the body's immune system attacks part of the peripheral nervous system," potentially leading to paralysis).

98. *Quadriplegia*, CLEV. CLINIC (Aug. 10, 2022), https://my.clevelandclinic.org/health/symptoms/23974-quadriplegia-tetraplegia [https://perma.cc/V5NM-EU6X] (explaining that cervical spine injuries can result in quadriplegia, involving a permanent partial or complete loss of feeling and movement below the shoulders and neck).

99. Lewis et al., *supra* note 58, at 114–15.

100. *Id.* at 114.

101. *Id.*

102. *Id.*

Today, all fifty states recognize the UDDA's whole-brain criteria for brain death, either statutorily or judicially,[103] and the AAN's standards are used as the baseline for brain death determinations throughout the United States and beyond.[104] Yet fundamental inconsistencies persist among states' different UDDA variations.[105] These include the use or absence of the language "including the brain stem," the types of professionals qualified to determine brain death, the particular medical standards used, and states' responses to families' objections to brain death.[106] As these inconsistences show, the concept of brain death is still up for debate, still unsettled, still evolving. And this evolution has been the subject of recent controversy.

B. To Revise or Not to Revise?

In 2020, the Uniform Law Commission (ULC) created a Study Committee to consider whether the UDDA should be revised.[107] The Study Committee noted that "portions of the UDDA do not align with current medical practice," so it called for a Drafting Committee to address four issues: (1) the medical criteria used to determine death, (2) the appropriateness of "irreversible" versus "permanent," (3) the brain region that matters when determining neurological death, and (4) other issues, such as accommodating religious objections.[108] The new, resulting UDDA would then be called the rUDDA, with "r" standing for "revised."[109]

Nonetheless, from January to July of 2023, the Drafting Committee received sixty-five letters from concerned parties with conflicting views.[110] The debates became "so contentious" that the Drafting Committee was unable to reach a consensus about what revisions, if any, to make.[111] Thus, the ULC paused the revision process, leaving many issues unresolved.[112]

With the lingering possibility of a future rUDDA, it is crucial to consider the legal, medical, religious, and social issues underlying the current UDDA, as

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103. Lewis et al., *supra* note 76, at 13 (including a detailed list of statutes and cases that have incorporated or adopted the UDDA).

104. Lewis et al., *supra* note 58, at 123.

105. Junn & Hwang, *supra* note 21, at 721.

106. *Id.*; Lewis et al., *supra* note 76, at 13.

107. Samuel A. Thumma et al., *Issues Memorandum: Determination of Death Act (20__), Uniform*, UNIF. L. COMM'N (June 22, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "2023 Annual Meeting—Draft and Issues Memorandum").

108. *Id.*

109. *Id.*

110. Lucy Grelle, *Comments—Various Authors—January 2023 Through July 2023*, UNIF. L. COMM'N (May 30, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

111. Stein, *supra* note 25.

112. *Id.*

well as the diverse viewpoints of stakeholders who contributed to the Drafting Committee's debates. These issues and voices cover a broad range of topics and address both the potential harms and benefits that could result from revisions to this longstanding legal and medical precedent.

II. THE UDDA'S CONTROVERSIAL ISSUES AND LEGAL IMPLICATIONS

A. Religious Objections

As evidenced by the decades-long controversy surrounding brain death that continues to this day, what constitutes death is highly dependent upon people's values and beliefs.[113] This is rooted in the fact that American culture places great importance on religious freedom and personal autonomy.[114] However, despite this culture of individuality and empowerment, the decision to test for brain death is usually left to the discretion of providers.[115] And once a patient has been declared brain dead, providers have no ethical duty to maintain life support.[116] For some patients and their families, this creates a profound moral dilemma.[117]

Those who have expressed religious objections to brain death include the Japanese Shinto, Muslims, Roman Catholics, Orthodox Jews, Buddhists, and certain Indigenous cultures.[118] Not all individuals within these groups oppose brain death, but those who do only believe in the validity of cardiac death and object to withdrawing life support after a determination of brain death.[119]

Some object based on their beliefs about the soul's relationship to the body. For the Japanese Shinto, body and soul are interconnected, so if the body is otherwise healthy, the death of the brain is not the equivalent of "true death" because the soul lives on.[120] Similarly, Muslims and Roman Catholics believe that death occurs when the soul leaves the body, although precisely when this happens is not clearly defined.[121] Some Muslims accept brain death but believe that no legal consequences should occur until patients' respiration and

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113. Eran Segal, *Religious Objections to Brain Death*, 29 J. CRITICAL CARE 875, 875 (2014).

114. Robert A. Burt, *The Medical Futility Debate: Patient Choice, Physician Obligation, and End-of-Life Care*, 5 J. PALLIATIVE MED. 249, 250 (2002).

115. Pope, *supra* note 45, at 309 (citing Ariane K. Lewis & Thaddeus M. Pope, *Physician Power to Declare Death by Neurologic Criteria Threatened*, 26 NEUROCRITICAL CARE (2017)).

116. *Id.* at 308.

117. *Id.* at 316.

118. Lewis et al., *supra* note 58, at 122; Shah, *supra* note 26, at 330 (citation omitted).

119. Pope, *supra* note 45, at 291.

120. Yuri Terunuma & Bryan J. Mathis, *Cultural Sensitivity in Brain Death Determination: A Necessity in End-of-Life Decisions in Japan*, NAT'L LIBR. OF MED. (May 13, 2021), https://pmc.ncbi.nlm.nih.gov/articles/PMC8120912 [https://perma.cc/AU9K-UWUN].

121. Andrew C. Miller et al., *Brain Death and Islam*, NAT'L LIBR. OF MED. (Oct. 2014), https://pmc.ncbi.nlm.nih.gov/articles/PMC4188144 [https://perma.cc/T3CJ-XLXX]; Joseph Meaney, *Unacceptable Revisions to the Uniform Determination of Death Act*, NAT'L CATH. BIOETHICS CTR. (June 13, 2023), https://www.ncbcenter.org/messages-from-presidents/uddarevisions [https://perma.cc/7JCM-XTQA].

circulation have also ceased.[122] And some Roman Catholics accept brain death yet emphasize that rigorous tests must be used to have "moral certitude" that the entire brain, including the hypothalamus, has ceased working.[123]

Others object based on beliefs unrelated to the soul. In Orthodox Judaism, the Torah links life to the presence of breath, so "as long as a person breathes, the heart functions, and the blood circulates, death has not yet occurred."[124] One rabbi has argued that "the function of the brain . . . is of more importance than the beating of a heart,"[125] but this is not the majority opinion among Orthodox Jews.[126] Buddhists, like Orthodox Jews, look beyond brain function when defining death.[127] In Buddhism, death is determined by the absence of vitality (i.e., metabolic processes), body heat, and consciousness, so a loss of consciousness alone does not constitute death.[128] Within some Indigenous cultures, brain death due to an accident or war injury is accepted, but it may be difficult to accept brain or cardiac death when it results from disease.[129] This is partially because disease is viewed as "a disturbance in the relationship among self, spiritual forces, community and environment," and disturbances may only be temporary.[130] Finally, for many individuals, regardless of their religious background, the possibility of miracles provides hope.[131] According to the Pew Research Center, nearly eighty percent of adults in the United States believe in miracles and, thus, may not be deterred by the idea of medical futility.[132]

1. The Free Exercise Clause.—Implicated by these various religious objections to the legal definition of brain death is the First Amendment, which states in relevant part that "Congress shall make no law respecting an establishment of religion, or *prohibiting the free exercise thereof* . . . ."[133] To determine whether a violation of the Free Exercise Clause has occurred, courts

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122. Miller et al., *supra* note 121.

123. Meaney, *supra* note 121.

124. Miller et al., *supra* note 121.

125. Kenneth Shuster, *"When Has the Grim Reaper Finished Reaping?" How Embracing One Religion's View of Death Can Influence Acceptance of the Uniform Determination of Death Act*, 30 TOURO L. REV. 655, 660 (2014).

126. Miller et al., *supra* note 121.

127. Damien Keown, *Buddhism, Brain Death, and Organ Transplantation*, 17 J. BUDDHIST ETHICS 1, 12 (2010).

128. *Id.*

129. Yoshiko Yamashita Colclough & Gary M. Brown, *American Indians' Experiences of Life-Threatening Illness and End of Life*, NAT'L LIBR. OF MED. (Oct. 1, 2014), https://pmc.ncbi.nlm.nih.gov/articles/PMC4238934 [https://perma.cc/6MTD-GNUR]. This information comes from the background section of an exploratory study and only represents the health care values of some Indigenous cultures.

130. *Id.* (quoting KENNETH COHEN, HONORING THE MEDICINE: THE ESSENTIAL GUIDE TO NATIVE AMERICAN HEALING 16 (2003)).

131. Pope, *supra* note 45, at 289.

132. *U.S. Religious Landscape Survey: Religious Beliefs and Practices,* PEW RSCH. CTR., (June 1, 2008), https://www.pewresearch.org/religion/2008/06/01/u-s-religious-landscape-survey-religious-beliefs-and-practices [https://perma.cc/G7VX-KX73].

133. U.S. CONST. amend. I (emphasis added).

turn to the Religious Freedom Restoration Act (RFRA).[134] The federal RFRA states that "[g]overnment shall not substantially burden a person's exercise of religion even if the burden results from a rule of general applicability."[135] "Exercise of religion" is defined as "any exercise of religion, whether or not compelled by, or central to, a system of religious belief."[136] And to explain why a "rule of general applicability" could be problematic, the RFRA notes that "laws 'neutral' toward religion may burden religious exercise as surely as laws intended to interfere with religious exercise."[137]

The RFRA expressed this viewpoint in response to *Employment Division v. Smith*, where the United States Supreme Court "virtually eliminated" the requirement that the government justify burdens imposed on religious exercise by "neutral" or generally applicable laws.[138] The RFRA also superseded *Church of Lukumi Babalu Aye v. City of Hialeah*, where ordinances targeting only religious killings of animals yet permitting other types of animal killings violated the Free Exercise Clause by being "underinclusive."[139] In contrast to *Church of Lukumi Babalu Aye*, the RFRA does not require that government action target religious practices directly but only that it impose a substantial burden on those practices, thus restoring the "compelling interest" test from *Sherbert v. Verner*.[140]

In *Sherbert*, an employee was disqualified from receiving benefits and ultimately lost her job because she would not work on Saturdays, which were the Sabbath Day of her faith.[141] The United States Supreme Court noted that the requirement to work on Saturdays imposed a burden because it forced the employee "to choose between following the precepts of her religion and forfeiting benefits, on the one hand, and abandoning one of the precepts of her religion in order to accept work, on the other hand."[142] Employees who worshipped on Sundays, however, were statutorily protected from having to make that same kind of choice.[143] Having established that a substantial burden on the employee's free exercise of religion existed, the Court then held that the government must show (1) a "compelling state interest" for upholding the regulation and (2) that "no alternative [and less burdensome] forms of regulation" would protect that interest.[144] Nonetheless, the government's

134. Religious Freedom Restoration Act, 42 U.S.C. §§ 2000bb to 2000BB-4 (2025).
135. 42 U.S.C. § 2000bb-1(a).
136. 42 U.S.C. § 2000bb-2(4) (as defined under 42 U.S.C. § 2000cc-5(7)(A)).
137. 42 U.S.C. § 2000bb(a)(2).
138. 42 U.S.C. § 2000bb(a)(4).
139. Church of Lukumi Babalu Aye v. City of Hialeah, 508 U.S. 520, 543 (1993).
140. 42 U.S.C. § 2000bb(b)(1).
141. Sherbert v. Verner, 374 U.S. 398, 399, 404 (1963).
142. *Id.* at 404.
143. *Id.* at 406.
144. *Id.* at 406–07 (describing a level of judicial scrutiny now known as "strict scrutiny," although Justice Brennan did not refer to it as such within *Sherbert*).

interest in avoiding potential disruptions to the work schedule was "doubtful . . . to warrant a substantial infringement of religious liberties."[145]

In 2015, Indiana passed its own RFRA with the same provisions: if a governmental entity has "substantially burden[ed]" an individual's exercise of religion, that entity must show that the burden is (1) "in furtherance of a compelling governmental interest" and (2) the "least restrictive means" of furthering that interest.[146] Indiana's RFRA also goes a step further by allowing an individual to assert a violation of this statute as a claim or defense "regardless of whether the state or any other governmental entity is a party to the proceeding."[147] Thus, individuals can bring RFRA claims against private Indiana providers that are substantially burdening their exercise of religion in health care decisions, such as by forcing the withdrawal of life support against a patient's or family's religious beliefs. To avoid such life-altering RFRA violations and the lawsuits that could result, an exemption from brain death is needed within the UDDA.

2. A Complete Exemption from Brain Death.—While a few states have allowed temporary accommodations for objecting families, only one state, New Jersey, offers a complete religious exemption from brain death determinations.[148] This is intended for individuals who believe that "continued circulatory and respiratory activity, even if artificially sustained, is evidence of life."[149] New Jersey's exemption reads as follows:

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[.][150]

Thus, if a determination of brain death would violate the patient's "personal religious beliefs," as evidenced by information in the patient's medical records or as expressed by loved ones, the opt-out would allow death to be declared "solely upon the basis of cardio-respiratory criteria . . . ."[151]

This opt-out provision was life-changing for a young girl named Jahi McMath.[152] Jahi was a thirteen-year-old from California who experienced

145. *Id.* at 407.

146. IND. CODE § 34-13-9-8 (2025).

147. IND. CODE § 34-13-9-9 (2025).

148. Pope, *supra* note 45, at 318.

149. Alyssa A. DiRusso, *Life and Death Matters in Conflict of Laws*, 97 TUL. L. REV. 703, 719 (2023).

150. N.J. REV. STAT. § 26:6A-5 (2025).

151. *Id.*

152. *See* Janet L. Dolgin, *Choosing Death, Shaping Death: Assumptions About Disabilities, Race, and Death*, 25 QUINNIPIAC HEALTH L.J. 61, 89 (2022).

severe complications after a routine tonsillectomy.[153] Within days of her surgery, she was declared brain dead.[154] However, Jahi's mother, Nailah, noticed that Jahi still exhibited signs of life, such as the warmth of her body and the reactiveness of her feet.[155] Given these signs of life, Nailah said that it would go against her religious beliefs not to recognize and treat Jahi as a living human being.[156] Thus, Nailah filed for a temporary restraining order (TRO) to halt the removal of Jahi's ventilator and to have a gastric tube (for nutrition) and a tracheostomy tube (for breathing) inserted, which would have made it possible for Jahi to be transferred to another facility.[157] Nevertheless, the California court system only required the hospital to maintain the "status quo" of Jahi's treatment, which did not include any nutrition for Jahi.[158] Subsequently, Nailah felt compelled to consent to the issuance of a death certificate in order to obtain custody of Jahi's body.[159] She then moved with Jahi to New Jersey, where the religious exemption would allow Jahi to receive medical care.[160]

Taking these religious considerations into account, the Drafting Committee included a provision in the rUDDA that would allow for a patient or surrogate to object generally to a determination of death.[161] Subsections (a) and (b) of this provision read as follows:

> (a) The individual may object to a determination of death . . . .
>
> (b) An objection under subsection (a) must be documented in the individual's medical records [or through information provided to the health-care institution by the individual's surrogate].[162]

Subsection (c) provides that a "health-care institution shall . . . comply with the individual's choice that a determination of death not be made . . . ," but it stipulates that this choice "must be made before beginning the clinical

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153. Winkfield v. Child.'s Hosp. Oakland, No. C 13-5993 SBA, 2014 U.S. Dist. LEXIS 8560, at *1 (N.D. Cal. Jan. 22, 2014).

154. *Id.*

155. Examiner Staff, *A Personal Story of Representing Jahi McMath*, S.F. EXAM'R (Dec. 25, 2013), https://www.sfexaminer.com/lifestyles/a-personal-story-of-representing-jahi-mcmath/article_ce07c872-30b5-505d-9e9f-37d28a812ea6.html [https://perma.cc/T699-F9FS].

156. Complaint for Declaratory Relief & Request for Temporary Restraining Order & Injunctive Relief at 4, Winkfield v. Child.'s Hosp. Oakland, No. C 13-5993 SBA (N.D. Cal. Dec. 30, 2013).

157. *Id.* at 1.

158. Order Deferring in Part & Denying in Part Plaintiff's Application for a Temporary Restraining Order at 2, Winkfield v. Child.'s Hosp. Oakland, No. C 13-5993 SBA (N.D. Cal. Dec. 30, 2013).

159. Dolgin, *supra* note 152, at 88.

160. *Id.* at 89.

161. DETERMINATION OF DEATH ACT § 6 (UNIF. L. COMM'N, Redline Comparison Draft June 27, 2023).

162. *Id.* at § 6(a), (b).

evaluation for the determination of death . . . ."[163] Also, notably, no part of this opt-out provision requires that the objection be religious in nature.[164]

A general exemption like this is important because some individuals who object may not be religious. According to a Pew Research Center survey, forty-eight percent of adults in the United States identify as "spiritual" and twenty-two percent as "spiritual but not religious."[165] Over eighty percent of these spiritual individuals believe that humans have a soul or a spirit in addition to their physical body and that there is "something spiritual beyond the natural world."[166] These patients and surrogates, who have taken a more individualized approach to their spiritual lives, may have values that they hold just as deeply as those who practice an organized religion. When considering objections to brain death, this should not be overlooked.

B. Scientific Objections

"[B]iology suggests that brain death is not a valid conception of death," says Seema K. Shah, a professor of bioethics at the National Institutes of Health.[167] "If patients and families have very deeply held religious or moral views about the sanctity of life, it is reasonable for them to reject equating brain death and biological death."[168] It is also reasonable to reject brain death for scientific reasons. Dr. Paul Byrne, a neonatologist and clinical professor of pediatrics, holds the following: "To state that life has left the body when there is a beating heart, normal blood pressure, normal temperature, and normal color is false . . . . Many other evidences of being alive continue in those declared 'brain dead.'"[169]

For example, as Dr. Shewmon notes, a patient on a ventilator who does not show any signs of consciousness may still be able to circulate blood, digest food, excrete waste, grow and develop, regulate body temperature, heal wounds, fight infections, and even reproduce.[170] In addition to maintaining these various bodily functions, patients declared brain dead often demonstrate osmoregulation (maintaining an appropriate concentration of salt and water),[171] secrete vasopressin (preventing diabetes insipidus),[172] have ischemic penumbra (a

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163. *Id.* at § 6(c).

164. *Id.* at § 6.

165 . David O'Reilly, *What Does Being Spiritual Mean?*, PEW (May 29, 2024), https://www.pewtrusts.org/en/trust/archive/spring-2024/what-does-being-spiritual-mean [https://perma.cc/TAB4-NPSV].

166. *Id.*

167. Shah, *supra* note 26, at 331.

168. *Id.*

169. Paul A. Byrne & George M. Rinkowski, *"Brain Death" Is False*, 66 THE LINACRE Q. 42, 47 (1999).

170. Shewmon, *supra* note 79, at 467–68.

171. Nair-Collins & Miller, *supra* note 23, at 651.

172. James L. Bernat & Anne L. Dalle Ave, *Aligning the Criterion and Tests for Brain Death*, 28 CAMBRIDGE Q. OF HEALTHCARE ETHICS 635 (2019).

condition where neurons have survived in a low-blood-flow state),[173] and react to incisions for organ procurement with an increase in heart rate and blood pressure (perhaps indicative of pain).[174] Such a person is not dead, biologically speaking, yet may still be labeled "brain dead."[175]

Dr. Shewmon, whose statement challenging the rUDDA was endorsed by over one hundred experts,[176] takes issue with labeling living persons as legally dead.[177] To him, a living person is a "human organism [that] maintains its internal homeostasis to resist the tendency toward decay," meaning that the human organism is able to regulate "a whole host of mutually interdependent physiological functions."[178] Death, by contrast, only occurs when a patient's body can no longer "maintain or restore homeostasis."[179] Thus, to declare a patient dead whose body is maintaining homeostasis by engaging in osmoregulation and digestion, for instance, would be scientifically objectionable, contradicting a biological reality.

1. Brain Death as a Legal Fiction.—Given this biological reality, brain death is a legal fiction.[180] A legal fiction "exists when the law treats something known to be false (or not known to be true) as if it were true for a particular legal purpose."[181] In this case, the legal purpose for equating brain death with biological death is to permit the withdrawal of treatment and the donation of organs and to protect the individuals who make and carry out these decisions from liability.[182] Rather than openly acknowledging this fiction and its purposes, however, many providers promote brain death as a true reflection of reality.[183] This is what happened when a physician exclaimed to Jahi's McMath's family, "What don't you understand? She is dead, dead, dead."[184]

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173. *Id.*

174. Truog, *supra* note 36, at 1891.

175. *Id.* at 1897.

176. Michael Cook, *UDDA and RUDDA: Uproar Over Possible Change in Brain Death Criteria*, BIOEDGE (May 30, 2021), https://bioedge.org/uncategorized/udda-and-rudda-uproar-over-possible-change-in-brain-death-criteria [https://perma.cc/V54A-E66G].

177. D. Alan Shewmon et al., *Comments: D. Nguyen, D.A. Shewmon, M. Y. Rady, and Others*, UNIF. L. COMM'N (July 12, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

178. *Id.*

179. *Id.*

180. Shah, *supra* note 26, at 304.

181. *Id.*

182. *Id.* at 325 (discussing how this legal fiction allows for the withdrawal of life support and organ donation); Schiller, *supra* note 27, at 214 (discussing the protection of transplant surgeons from liability).

183. Charlie Camosy, *"Brain Death" at a Crossroads*, THE PILLAR (July 14, 2023), https://www.pillarcatholic.com/p/brain-death-at-a-crossroads [https://perma.cc/FT2W-MUL6].

184. Examiner Staff, *supra* note 155.

Several months later in New Jersey, Jahi showed more signs of life: her body underwent puberty, and she responded to her mother's voice.[185] Dr. Shewmon also visited Jahi and observed firsthand as Jahi moved her right arm in response to a command to do so.[186] Jahi's family recorded numerous videos of Jahi moving in response to verbal commands, and these videos were genuine according to forensics experts, who analyzed the videos for skeptics.[187] Dr. Shewmon then examined the videos and gave sworn testimony that Jahi was not brain dead but was, in fact, in a minimally conscious state.[188] Hence, for Jahi, the legal fiction of brain death had not only failed to represent her biological reality but had also jeopardized her right to life.

C. Testing for Brain Death

Another danger that affects patients' right to life is the lack of consensus and accuracy in brain death determinations. While it is true that the AAN's standards are considered the baseline "accepted medical standards" throughout the United States,[189] there is no regulatory body that enforces those standards.[190] Therefore, hospitals and providers often deviate from the norm.[191] This is why Ariane Lewis and her medical colleagues called for revisions to the UDDA in 2019.[192] They were concerned about diagnostic practices that varied "significantly," such as differences in whether ancillary tests were required and differences in apnea-test techniques.[193]

Ancillary tests serve to confirm the accuracy of brain death determinations, yet they are not legally required in most jurisdictions.[194] This means that the standard laboratory testing done before and after an apnea test to measure arterial carbon dioxide is not required, which could undermine the apnea test's accuracy.[195] Other ancillary tests that experts believe should be legally required include neuroimaging procedures to test for intracranial circulatory arrest (i.e., the complete stoppage of blood flow to the brain)[196] and laboratory testing to

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185. Rachel Aviv, *What Does It Mean to Die?*, NEW YORKER (Jan. 29, 2018), https://www.newyorker.com/magazine/2018/02/05/what-does-it-mean-to-die [https://perma.cc/999U-6MAS].

186. Nair-Collins & Miller, *supra* note 23, at 653 (citing Alan D. Shewmon, *Truly Reconciling the Case of Jahi McMath*, 29 NEUROCRITICAL CARE 165, 169 (2018)).

187. *Id.* at 652.

188. Declaration of D. Alan Shewmon, *supra* note 78, at 2.

189. Lewis et al., *supra* note 58, at 123.

190. Lewis et al., *supra* note 76, at 14.

191. David M. Greer et al., *Variability of Brain Death Policies in the United States*, 73 JAMA NEUROLOGY 213, 213 (2016).

192. Lewis et al., *supra* note 76, at 10.

193. *Id.* at 14.

194. Nair-Collins & Miller, *supra* note 23, at 650.

195. *Id.*

196. Bernat & Dalle Ave, *supra* note 172, at 637.

check for functioning of the hypothalamus (which regulates hormones).[197] Providers argue that the implementation of ancillary tests should be left to medical discretion and not become a legal requirement.[198] Nonetheless, there remains a "mismatch" between the medical and legal standards for brain death, such that providers only following the AAN's standards are not actually testing "all" functions of the "entire" brain.[199]

This mismatch was apparent in *In re Guardianship of the Person and Estate of Aden Hailu*.[200] Aden was a young woman who was declared brain dead after a surgery to remove her appendix.[201] Her father, who observed signs of life such as Aden squeezing his hand, contested her brain death diagnosis.[202] Siding with Aden's father, the Supreme Court of Nevada noted that the hospital had failed to "establish whether the AAN guidelines adequately measure[d] the extraordinarily broad standard laid out" by the UDDA.[203] And to permit the withdrawal of Aden's life support based on this "undeveloped record" would be an irreversible error.[204]

In addition to this mismatch between the UDDA's language and the AAN's standards, there is another testing concern: false positives and misdiagnoses as a result of "examiner error" are common when it comes to determining brain death.[205] In Indiana, only a physician can declare brain death, but some states also allow physician assistants and nurses to do so.[206] Furthermore, there is research showing that even physicians lack sufficient training in how to determine brain death.[207] Scholars have proposed solutions, such as learning modules, brain death simulations, and specialized credentialing.[208] In the meantime, however, informed consent about the inaccuracies and risks of brain death testing should be required.

1. Informed Consent for Apnea Testing.—Apnea tests are a required component of brain death determinations.[209] Nonetheless, since physicians do

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197. Meaney, *supra* note 121.

198. Jan K. Carney, *Comments: American College of Physicians*, UNIF. L. COMM'N (June 7, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

199. Pope, *supra* note 45, at 307.

200. *In re* Guardianship of Hailu, 361 P.3d 524 (Nev. 2015).

201. Siobhan McAndrew, *The Contested Death of Aden Hailu*, RENO GAZETTE J. (Mar. 29, 2016, 8:53 PT), https://www.rgj.com/story/news/2016/03/25/contested-death-aden-hailu/82269006 [https://perma.cc/3F8Q-8SMM].

202. *Id.*

203. *Hailu*, 361 P.3d at 531.

204. *Id.* at 532

205. Nair-Collins & Miller, *supra* note 23, at 653.

206. Lewis et al., *supra* note 58, at 118.

207. Popik, *supra* note 40.

208. Bernat & Dalle Ave, *supra* note 172, at 638.

209. David M. Greer et al., *Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Guideline: Report of the AAN Guidelines Subcommittee*, 101 NEUROLOGY 1112, 1121 (2023).

not classify brain death determinations as a "medical procedure," they generally do not seek consent prior to testing for brain death.[210] This means that they conduct apnea and other tests without explaining the "material risks" and "expected outcome" of the proposed testing to surrogates, thereby disregarding the requirements for informed consent.[211]

States are divided on this issue. In Montana, a district court held that the surrogate's consent was required before apnea testing because Montana's UDDA did not mandate or specifically grant health care providers the right to conduct a brain death examination.[212] In that same decision, it also held the following: (1) Montana patients have a state constitutional right "to choose or refuse" a brain death examination under "the personal autonomy component of [Montana's] individual privacy guarantees," and (2) parents have a "fundamental liberty interest" under the Fourteenth Amendment's Due Process Clause to make this decision on behalf of their children.[213] Nevada, by contrast, enacted a statute that explicitly states, "A determination of the death of a person . . . is a clinical decision that does not require the consent of the person's authorized representative or the family member with authority to consent . . . ."[214]

The current language of the rUDDA does not remedy this issue.[215] Although it requires "a reasonable effort to notify" surrogates that a brain death evaluation will occur, it neither requires consent nor grants providers an explicit right to conduct brain death determinations.[216] This lack of clarity is especially concerning because apnea testing can harm patients.[217]

Dr. Coimbra, a neurologist with a specialty in brain ischemia, illustrated this harm in his letter to the Drafting Committee.[218] He first explained that ischemic penumbra is a condition of reduced blood flow to the brain, which can potentially be reversed by giving a patient thyroid hormone replacement.[219] Further, he noted that some patients are deemed brain dead "precisely *because* they are not receiving a life-saving replacement of thyroid hormones."[220] He

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210. Lewis et al., *supra* note 76, at 15.

211. IND. CODE § 34-18-12-3 (2025).

212. *In re* Guardianship of A.C., No. DG-16-08, at 6–7 (Mont. Dist. Ct. Sep. 16, 2016).

213. *Id.* at 7.

214. NEV. REV. STAT. § 451.008(1) (2025).

215. UNIF. L. COMM'N, *supra* note 38.

216. *Id.*

217. *E.g.*, Paul A. Byrne & Christine M. Zainer, *Comments: Christine Zainer and Paul Byrne*, UNIF. L. COMM'N (July 26, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

218. Cicero G. Coimbra, *Comments: Cicero G. Coimbra*, UNIF. L. COMM'N (July 24, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

219. *Id.*

220. *Id.* (emphasis added).

then told the story of one such patient, a woman in her thirties who had been clinically determined "brain dead" by a different neurologist.[221] After Dr. Coimbra tested her thyroid levels and administered the appropriate amount of hormones, she was able to be extubated eight days later and to communicate with her family by lip reading within a few months.[222] Thus, she was not dead.

Even more concerning is the fact that others like Dr. Coimbra's patient may be declared "brain dead" incorrectly and then subjected to apnea testing. According to Dr. Coimbra, apnea testing causes hypotension, "thereby further reducing brain circulation and aggravating brain damage."[223] Apnea testing can also "collapse brain circulation," causing irreversible brain damage.[224] Thus, the apnea testing itself can cause brain death in a formerly alive patient.

D. Organ Donorship by Brain Death

While heightening the accepted medical standards and requiring informed consent for brain death testing would help to prevent testing-related harms, these changes could also result in fewer organ donations.[225] Three transplantation organizations wrote a joint letter to the Drafting Committee, expressing concerns about rUDDA provisions that would delay or allow an opt-out to brain death determinations.[226] They feared that these provisions would have a "chilling effect" on the lives of patients with end-stage organ diseases.[227] The American College of Physicians, however, cautioned that "there is [a] risk that determination of death will be driven, explicitly or implicitly, by interest in obtaining organs for transplantation," so keeping these issues separate is "critical" to avoid undermining trust in the organ transplantation system.[228]

The Association of American Physicians and Surgeons, Inc., also cautioned that there is a risk of coercion when patients, as in Canada, are euthanized before becoming organ donors.[229] Canada offers medical assistance in dying (MAiD), where an approved practitioner either administers a substance that causes death

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221. *Id.*

222. *Id.*

223. *Id.*

224. *Id.*

225. Bernat & Dalle Ave, *supra* note 172, at 638.

226. Elizabeth A. Pomfret et al., *Comments: American Society of Transplant Surgeons, American Society of Transplantation, and Organization for Donation and Transplant Professionals*, UNIF. L. COMM'N (July 18, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

227. *Id.*

228. Carney, *supra* note 198.

229. Sheila Page, *Comments: Association of American Physicians and Surgeons, Inc*, UNIF. L. COMM'N (June 22, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

or prescribes a drug that patients can take themselves to end their lives.[230] To participate in MAiD, patients must make a voluntary request that is not the result of "outside pressure or influence."[231] Nonetheless, this protocol is not a perfect science. One example of coercion is the experience of Heather Hancock, a patient with cerebral palsy, who was pressured by a nurse to consider MAiD.[232] The nurse told her, "You're being selfish. You're not living, you're merely existing."[233] According to Shapiro, author of *Euthanasia by Organ Donation*, such concerns are not isolated to Canada, given that MAiD is "a more transparent view" of how the United States currently approaches organ donations.[234]

As a case in point, Dave Adox, a patient from New Jersey who was diagnosed with ALS, sought to donate as many of his organs as possible once his disease had progressed.[235] After some difficulty finding a hospital that would assist him, he finally got his wish, spending the end of his life surrounded by family as he was sedated and then disconnected from life support.[236]

Although not usually openly acknowledged, Dave's MAiD-like approach to dying is commonplace in the United States. Patients declared "brain dead" are kept alive via mechanical ventilation to preserve their organs for donation.[237] Their families can spend time with them.[238] Then, while their hearts are still beating, their life support is withdrawn, and their organs are procured—either immediately if they are a heart donor or after cardiac death has occurred.[239] To be clear, the removal of their life support and organs is the cause of their death.[240]

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230. *Medical Assistance in Dying: Overview*, GOV'T OF CAN. (Oct. 28, 2024), https://www.canada.ca/en/health-canada/services/health-services-benefits/medical-assistance-dying.html [https://perma.cc/GQ23-V7ZA].

231. *Id.*

232. Alex Schadenberg, *Canadian Woman Pressured to "Choose" Euthanasia. She Was Told that She Was Selfish for Living*, EUTHANASIA PREVENTION COAL. (July 12, 2024), https://alexschadenberg.blogspot.com/2024/07/canadian-woman-pressured-to-choose.html [https://perma.cc/8B4Y-2B35].

233. *Id.*

234. Shapiro, *supra* note 22, at 167.

235. Karen Shakerdge, *A Dying Man's Wish to Donate His Organs Get Complicated*, NAT'L PUB. RADIO (Dec. 26, 2016, 4:30 ET), https://www.npr.org/sections/health-shots/2016/12/26/499494248/a-dying-man-s-wish-to-donate-his-organs-gets-complicated [https://perma.cc/3CGH-9S4Q].

236. *Id.*

237. Pauline M. Todd et al., *Organ Preservation in a Brain Dead Patient: Information Support for Neurocritical Care Protocol Development*, 95 J. MED. LIBR. ASS'N 238, 238 (2007).

238. Pope, *supra* note 45, at 277.

239. Nair-Collins & Miller, *supra* note 23, at 654.

240. Shapiro, *supra* note 22, at 165; Schiller, *supra* note 27, at 214.

E. Violations of Patients' Right to Life

The Fourteenth Amendment declares that no state shall "deprive any person of life . . . without due process of law."[241] Nonetheless, despite this protection of patients' right to life, some states allow physicians to withdraw life support against surrogates' instructions, as seen in Indiana with Treasure Perry.[242] Per policy at the Riley Hospital for Children, two physicians conducted a brain death examination and believed Treasure to be dead.[243] Treasure's mother, who was also her surrogate, observed signs of life and tried to get Treasure transferred to another hospital.[244] However, no hospital would accept Treasure without a tracheal tube, which the Riley Hospital refused to insert after declaring brain death.[245] Treasure's physician also refused to visit Treasure to check for changes in her status "because deceased patients are not rounded on."[246]

When considering the merits of Treasure's case, Judge Kurt M. Eisgruber of the Marion Superior Court made a factual finding that "[t]here is no hope of [sic] that Perry will have any brain activity in the future."[247] Judge Eisgruber also referred to Treasure as a "dead person" who was on "mechanical ventilation, not life support, as no life support exists for a deceased person."[248] And in denying her a tracheal tube, Judge Eisgruber noted "downsides to providing medical therapy to a deceased person . . . [such as] the risks (no benefits) associated with medical therapies, and the toll on the healthcare team, specifically moral distress."[249] Judge Eisgruber expressed particular concern that health care workers would leave their profession due to this distress, yet he did not express a similar concern about the distress of Treasure's family.[250]

Decisions like this pose a threat to patients' constitutional right to life because "there is no way of knowing how many patients might recover to the minimally conscious state" after brain death is declared.[251] This is unknown because physicians or surrogates usually withdraw life support or consent to organ donation quickly, without giving patients a chance to recover.[252] Nevertheless, if given more time, some patients in a coma become minimally conscious or enter a vegetative state instead of dying, and around half of patients

241. U.S. CONST. amend. XIV, § 1.
242. *In re* Perry, No. 49D06-2208-MI-026530 (Ind. Super. Ct. Marion Cnty. Aug. 11, 2022).
243. *Id.* at 2–3.
244. Ortiz, *supra* note 12.
245. *Id.*
246. *Perry*, No. 49D06-2208-MI-026530, at 4.
247. *Id.* at 3.
248. *Id.* at 4–5.
249. *Id.* at 4.
250. *Id.*
251. Nair-Collins & Miller, *supra* note 23, at 653.
252. Truog, *supra* note 36, at 1894.

who are vegetative eventually recover consciousness.[253] While patients in a coma may still exhibit some reflexes, there is no other indication of their consciousness, which puts them at risk of being misdiagnosed.[254] Similarly, patients with locked-in syndrome are quadriplegic and may only be able to blink, yet they are fully conscious.[255] They, too, are at risk of misdiagnosis. Dr. Owen, the neurologist who examined Juan, has seen this time and again, especially with Kate.[256]

1. The Harm of Value Judgments.—Kate had contracted a viral condition that caused her to lapse into a coma due to widespread inflammation of her brain and spinal-cord tissue.[257] Within a few weeks, she had improved and was declared vegetative, but she still "showed no signs of inner life."[258] Dr. Owen conducted testing with a PET scanner and was surprised to find that Kate's brain was responding to visual input.[259] Months later, Kate started to speak again and, in time, visited with Dr. Owen.[260] She told him that she remembered becoming conscious again, having emotions, and feeling "incredibly angry" because most of her caretakers viewed her as "just a body."[261]

Viktor Frankl, a neurologist and Holocaust survivor, expressed concerns about this objectification and the value judgments that providers make.[262] He said, "With each patient, the doctor does not have the human being but the 'case' in front of him," and this "medical jargon" causes a "tendency for dissociation by doctors . . . and their objectification of human beings."[263] He went on to question, "Is the doctor ever employed by society to kill? Doesn't he rather have the task to save where he can and to give care whenever he is unable to heal?"[264] If providers made value judgments about whether patients were fit to live, patients and their families would lose trust in the medical profession because "no one would ever know whether the doctor was still approaching them as helper and healer or already as judge and executioner."[265]

Jahi's family expressed this same sentiment after being repeatedly pressured in California to consent to organ donorship, feeling like the hospital cared more

253. Sara Buscher, *Comments: Euthanasia Prevention*, UNIF. LAW COMM'N (Mar. 14, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—January 2023 through July 2023").

254. J.T. Giacino et al., *The Minimally Conscious State: Definition and Diagnostic Criteria*, 58 NEUROLOGY 349, 350 (2002).

255. *Id.*

256. OWEN, *supra* note 1, at 40.

257. *Id.* at 28.

258. *Id.* at 28–29.

259. *Id.* at 31.

260. *Id.* at 37.

261. *Id.* at 39.

262. VIKTOR E. FRANKL, YES TO LIFE IN SPITE OF EVERYTHING 68, 73 (2019).

263. *Id.* at 68.

264. *Id.* at 73.

265. *Id.*

about having an organ donor than it cared about Jahi.[266] This distrust in the medical system is especially prevalent among "individuals from disadvantaged or minority backgrounds," including people of color like Jahi, Aden, and Treasure.[267] Frankl also saw it in Nazi concentration camps and mental institutions, where people who were not physically able to work were "judged to be unworthy of life" and murdered.[268] Furthermore, this mentality extended beyond Nazi Germany to the United States, as seen in *Buck v. Bell*, a United States Supreme Court decision that referred to people with disabilities as "defectives" and "imbeciles" and legally upheld their forced sterilization.[269] Indiana, in fact, passed the first eugenics sterilization legislation in the world in 1907.[270]

Value judgments about people of color and people with disabilities are particularly dangerous in medical settings, where their Fourteenth Amendment right to life is at stake.[271] This is because patients who are declared dead lose "basic human rights," and there is no longer a duty for providers to treat them.[272] Thus, a death determination holds serious consequences.

Additionally, if "irreversible" were changed to "permanent," the right to life of patients with disabilities would be jeopardized.[273] This is because "irreversible" means that no medical intervention can possibly help, whereas "permanent" means that no further medical interventions will be tried.[274] Allowing death to be declared based on a choice to stop trying interventions opens the door for more "quality-of-life judgments" about patients.[275] As award-winning author Katherine Schiller has observed, "Faced with patients who doctors (and society) would prefer to be treated as if they were [dead], proponents chose to expand the definition of death to include them rather than carving out exceptions to the rules for living people."[276]

Dr. Truog has emphasized that the question of "whether someone is dead" is entirely different from the question of "whether a life is worth living."[277] Regarding the worth of life for people with severe disabilities, one study showed that seventy-two percent of patients with locked-in syndrome indicated that they

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266. Dolgin, *supra* note 152, at 91.

267. Truog, *supra* note 36, at 1911.

268. FRANKL, *supra* note 262, 88.

269. Buck v. Bell, 274 U.S. 200, 205, 207 (1927).

270. *Indiana Eugenics: History & Legacy, 1907-2007*, SCHOLARWORKS INDIANAPOLIS, https://scholarworks.indianapolis.iu.edu/browse/title?scope=4e5f76bf-5f6c-4328-82c6-d6327848d4d1[https://perma.cc/ET8S-KFSL] (last visited Feb. 11, 2025).

271. U.S. CONST. amend. XIV, § 1.

272. Pope, *supra* note 45, at 274 (quoting PETER SINGER, RETHINKING LIFE AND DEATH: THE COLLAPSE OF OUR TRADITIONAL ETHICS 22 (1994)).

273. Popik, *supra* note 40.

274. *Id.*

275. *Id.*

276. Schiller, *supra* note 27, at 208.

277. Truog, *supra* note 36, at 1897.

were happy, an unexpected result.[278] It may not even be what those patients expected, which is especially concerning if any of them had completed an advance directive, such as a "do not resuscitate" (DNR) order, prior to becoming locked in.[279]

During her lecture for the Fairbanks Center for Medical Ethics, Attorney Emily Munson of Indiana Disability Rights voiced a related concern—namely, that people who are newly disabled may not be in the best position to assess whether they could be happy living with a disability.[280] Some of the reasons for this include the fact that newly disabled individuals may have depression, intensive care psychosis, a head injury, or an electrolyte imbalance that could temporarily affect their complex decision-making capabilities.[281] Furthermore, if patients, their families, or their providers have internalized any of society's prejudices against people with disabilities, they may underestimate their potential to be happy and live meaningful lives.[282]

As someone who has personal experience navigating life with a disability, Attorney Munson explained that it takes time for newly disabled individuals to adjust.[283] More precisely, she said, "We see overwhelmingly in studies that, after about three weeks, people [who did not initially wish to live] change their minds."[284] This is because they need time to grieve the loss of their former identity.[285] They also may not realize that assistive technology, accessible housing, and other resources exist and are available to them unless they talk with another, "similarly-situated" individual who has already navigated the life transition that they now face.[286]

Thus, value judgments made in haste about the happiness or worth of patients' lives can be harmful, even if made by the patients themselves. After obtaining needed support, overcoming depression, looking beyond society's prejudices, or regaining their full decision-making capacity, patients' views may change. They may surprise themselves and society by wishing to live. And Frankl urged that it is wrong to deny life to any patient who has a will to live[287]—that is, it is wrong to "deprive any person of life . . . without due process of law."[288]

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278. OWEN, *supra* note 1, at 186.

279. *Id.* at 187.

280. Emily Munson, *Rethinking Informed Consent After Traumatic Spinal Cord Injury*, FAIRBANKS CTR. FOR MED. ETHICS (Jan. 18, 2017), https://www.youtube.com/watch?v=doADLh6-uNk [https://perma.cc/UA5F-PRWK].

281. *Id.*

282. *Id.*

283. *Id.*

284. *Id.*

285. *Id.*

286. *Id.*

287. FRANKL, *supra* note 262, at 78.

288. U.S. CONST. amend. XIV, § 1.

III. UDDA PROTECTIONS FOR VULNERABLE PATIENTS IN INDIANA

For all of the legal, medical, religious, and social reasons outlined above, Indiana should amend its UDDA to provide the maximum amount of protection for vulnerable patients by adopting these four interrelated provisions: (1) a complete exemption from brain death, including for nonreligious reasons; (2) the continued use of "irreversible"; (3) "accepted medical standards" for brain death that are heightened, statutorily standardized, and updated periodically as technology advances; and (4) a requirement of informed consent for apnea testing. There should also be a regulatory mandate that requires all medical personnel, attorneys, and others who counsel about the option to donate anatomically to explain that brain death is a legal fiction.

A. Complete Exemption from Brain Death

Patients and their surrogates should have the option to opt out of brain death determinations, regardless of their reasoning. For some, withdrawing life support from patients with "continued circulatory and respiratory activity, even if artificially sustained," goes against their religious beliefs.[289] This would be the equivalent of murdering their loved ones, whether by starvation, dehydration, or oxygen deprivation. For others who are spiritual yet nonreligious, they may have moral or scientific objections, especially given brain death's status as a legal fiction and the prevalence of false positives and misdiagnoses due to examiner error.[290]

Regarding religion, Indiana providers should heed the First Amendment's Free Exercise Clause,[291] as claims of free exercise violations can be brought against them under Indiana's RFRA when they prohibit the exercise of religious beliefs in health care decisions.[292] The ability to live out one's religious beliefs by rejecting a brain death determination and seeking continued life-saving care, for instance, is an "exercise of religion."[293] Viewed through the lens of *Sherbert*, refraining from withdrawing life support due to religious views about the sanctity of life is analogous to refraining from working on Saturdays due to the holiness of the Sabbath.[294] Moreover, when life support is set to be withdrawn against a patient's or family's religious beliefs, this imposes a "substantial[] burden" on the patient's family.[295] To hold steadfast to their beliefs, they may need to retain legal counsel[296] or relocate to New Jersey, where a religious

289. DiRusso, *supra* note 149, at 719.
290. Nair-Collins & Miller, *supra* note 23, at 653.
291. U.S. CONST. amend. I.
292. IND. CODE §§ 34-13-9-8 to -9 (2025).
293. 42 U.S.C. § 2000bb-2(4) (as defined under 42 U.S.C. § 2000cc-5(7)(A)).
294. Sherbert v. Verner, 374 U.S. 398, 399 (1963).
295. IND. CODE § 34-13-9-8 (2025).
296. *In re* Perry, No. 49D06-2208-MI-026530 (Ind. Super. Ct. Marion Cnty. Aug. 11, 2022).

exemption exists, leaving behind their employment, housing, and social support system.[297]

In addition, Indiana providers would be hard-pressed to meet the demands of strict scrutiny in RFRA cases involving objections to brain death. First, while saving patients with end-stage organ diseases would likely qualify as a "compelling" interest,[298] accomplishing this goal by taking the lives of heart-beating organ donors would be an "underinclusive" policy because it would only preserve the lives of some patients.[299] Second, a less burdensome way of saving patients with end-stage organ diseases does exist—namely, allowing patients with terminal illnesses, like Dave, to voluntarily consent to life-saving organ donations.[300]

To avoid these RFRA issues, Indiana legislators should adopt language within Ind. Code § 1-1-4-3 that allows for a complete exemption from brain death, which could read as follows:

A patient or surrogate may object to a determination of brain death at any time. An objection must either be documented in the patient's medical records or communicated to the health care institution by the patient or the patient's surrogate. After an objection is made, death shall only be declared, and the time of death fixed, on the basis of cardio-respiratory criteria.

This language does not necessitate any evidence of a patient's religious beliefs, which could result in litigation, nor does it require that an objection be made before brain death has been declared, which providers may not make possible for surrogates. It also allows for non-religious objections. In these ways, it safeguards vulnerable patients' lives and personal beliefs.

B. Keeping "Irreversible," Abandoning "Permanent"

The standard of "irreversible" should never be replaced by "permanent." This one-word revision could result in the legally permissible euthanasia of multiple groups of *living* patients, including those who are minimally conscious, vegetative, locked-in, comatose, or have other disabilities that society devalues.[301] The Arc, an organization that advocates for people with disabilities, fears that this change would lead to a "better dead than disabled" mentality.[302] Since "permanent" says nothing about the irreversibility of a patient's condition

297. Dolgin, *supra* note 152, at 89.

298. IND. CODE § 34-13-9-8 (2025).

299. Church of Lukumi Babalu Aye v. City of Hialeah, 508 U.S. 520, 543 (1993).

300. Schiller, *supra* note 27, at 216; Truog, *supra* note 36, at 1905–06. Although beyond the scope of this Note, the idea of allowing patients with terminal illnesses to voluntarily consent to dying by organ donation in order to save the lives of others is an interesting proposition to consider, provided that strong safeguards could be put into place to prevent coercion.

301. Schiller, *supra* note 27, at 212.

302. Marty Ford, *Comments: The Arc*, UNIF. L. COMM'N (July 11, 2023), https://www.uniformlaws.org/home (search for "Determination of Death Committee"; then select "Determination of Death Committee," followed by "Documents" and then "Comments—Various Authors—August 2023 through December 2023").

and simply represents a choice to stop medical interventions, it gives providers and surrogates power to discriminate and euthanize based on their own value judgments about what constitutes a meaningful life.[303]

Recently, Indiana has taken some conflicting stances on the right to life. For instance, Indiana has effectively banned abortion since August 2023 to protect the right to life of unborn babies.[304] Nonetheless, Indiana resumed executions in December 2024 after a fifteen-year pause, holding that some criminals did not have a right to life.[305] Thus, Indiana is poised to consider both sides of the right-to-life debate. When it comes to brain death determinations, Indiana should safeguard patients' right to life by keeping "irreversible" within Ind. Code § 1-1-4-3 indefinitely. This is crucial because voiceless patients, much like unborn babies, are not in a position to defend themselves, but they do have constitutional rights.[306]

C. Heightened "Accepted Medical Standards"

The "accepted medical standards" for brain death should become heightened, statutorily standardized, and updated periodically as technology advances. Firstly, stricter standards are needed because the current required, clinical-only testing does not assess "*all* functions of the *entire* brain, including the brain stem."[307] Indiana's "Statewide Guidelines for the Establishment of Brain Death," just like the AAN guidelines, do not require any ancillary testing.[308] This is problematic because conditions like Guillain-Barré syndrome and high cervical spine injury can mimic brain death.[309] Failure to test for intracranial circulatory arrest and hypothalamic function could also lead to false positives and misdiagnoses.[310] Patients like Juan, Kate, and Jahi, who each made unexpected recoveries, were at risk of being declared dead prematurely because of their initial inability to respond to stimuli.[311] And yet, despite this potential for misdiagnosis, the current guidelines allow providers like Treasure's

303. Popik, *supra* note 40.

304. *Abortion Access in Indiana,* ACLU OF IND., https://www.aclu-in.org/en/abortion-access-indiana [https://perma.cc/LZY6-BS4D] (last visited Feb. 11, 2025).

305. Daniel Carson, *Will There Be More Executions in Indiana in 2025?*, 35 IND. LAW. 1, 1 (Jan. 15–18, 2025).

306. U.S. CONST. amend. XIV, § 1.

307. Uniform Determination of Death Act, IND. CODE § 1-1-4-3(a)(2) (2025) (emphasis added).

308. Emil L. Weber, *Statewide Guidelines for the Establishment of Brain Death*, IND. STATE MED. ASS'N, https://www.ismanet.org/pdf/convention/09-01outline.pdf [https://perma.cc/U7Z6-LV83] (last visited Feb. 11, 2025).

309. Lewis et al., *supra* note 58, at 114–15.

310. *See* Bernat & Dalle Ave, *supra* note 172, at 637–38.

311. PRESIDENT'S COMM'N, *supra* note 69, at 25.

physician to avoid doing their due diligence, refusing to "round" on "deceased" patients to check for changes in their status.[312]

Currently, Ind. Code § 1-1-4-3 does not specify what its "accepted medical standards" should be.[313] This needs to change by statutorily requiring an EEG, relevant laboratory testing, and neuroimaging, which would provide extra safeguards against life-or-death clinical mistakes. Giving statutory authority to the standards would also protect physicians and health care facilities from litigation that questions the validity of the testing methods employed.[314] The authority to update these standards as technology advances could then be delegated to an administrative agency, which would periodically meet to discuss and propose revisions.[315] Additionally, whenever possible, fMRI technology and assessment protocols, such as those that Dr. Owen has created, should be used to search for otherwise unnoticeable signs of life.[316]

D. Informed Consent for Apnea Testing

Informed consent for apnea testing should be statutorily required within Ind. Code § 1-1-4-3. In Indiana, informed consent involves explaining the "material risks" and "expected outcome" of testing to patients or their surrogates.[317] As Dr. Coimbra has explained, the material risks of apnea testing include hypotension, "thereby further reducing brain circulation and aggravating brain damage," and the potential to "collapse brain circulation," making the damage irreversible.[318] Therefore, apnea testing can cause irreparable harm to a patient who is still alive.

Moreover, apnea testing done without ancillary laboratory tests may also be inaccurate.[319] And given that the expected outcome of apnea testing is a brain death declaration, resulting in the withdrawal of life support and other treatments as well as the loss of basic human rights, these further risks should be discussed with surrogates.[320] This aligns with Montana's holding that surrogates must consent before apnea testing is done, given that Montana's UDDA does not explicitly grant providers the right to conduct a brain death exam.[321] Similarly, Indiana's UDDA does not explicitly grant providers such a right, so consent should also be required in Indiana.[322]

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312. *In re* Perry, No. 49D06-2208-MI-026530, at 4 (Ind. Super. Ct. Marion Cnty. Aug. 11, 2022).

313. Uniform Determination of Death Act, IND. CODE § 1-1-4-3 (2025).

314. *In re* Guardianship of Hailu, 361 P.3d 524, 531 (Nev. 2015).

315. Lewis et al., *supra* note 76, at 18.

316. OWEN, *supra* note 1, at 158.

317. IND. CODE § 34-18-12-3 (2025).

318. Coimbra, *supra* note 218.

319. Nair-Collins & Miller, *supra* note 23, at 650.

320. Pope, *supra* note 45, at 274.

321. *In re* Guardianship of A.C., No. DG-16-08, at 7 (Mont. Dist. Ct. Sep. 16, 2016).

322. Uniform Determination of Death Act, IND. CODE § 1-1-4-3 (2025).

E. Disclosure of Brain Death as a Legal Fiction

All medical personnel, attorneys, and others who provide counsel about the option to donate anatomically should be required to explain that brain death is a legal fiction. As discussed above, a legal fiction exists when the law treats a known falsity as if it were true "for a particular legal purpose."[323] Under Indiana law, however, informed consent cannot be based on a falsity: it must involve a truthful explanation to the decisionmaker about the "general nature of the patient's condition."[324] Telling a potential organ donor or surrogate that brain death *is* biological death is not a truthful description of the donor's condition. Rather, heart-beating patients with bodies maintaining homeostasis in various ways remain alive until the transplant surgeon is ready; then they die from the withdrawal of life support and the procurement of their organs.[325]

"One of the hallmarks of the scientific method is a commitment to follow the truth wherever it may lead," says Dr. Truog, but the medical profession's "unwillingness . . . to engage in transparent and open dialogue" about the true reality of brain death is a "significant breach" of trust.[326] It is also a significant danger for people with disabilities, providing "ethical cover" for devaluing and ending their lives, thus highlighting the need for increased transparency.[327]

CONCLUSION

Determining brain death without violating patients' fundamental rights is like trying to navigate a minefield. Without guidance along the way, lives will be lost. This is why Indiana's UDDA needs a comprehensive set of protections for vulnerable, voiceless patients, including (1) a complete exemption from brain death, (2) the continued use of "irreversible," (3) heightened and standardized "accepted medical standards," and (4) a requirement of informed consent for apnea testing. A regulatory mandate requiring acknowledgment of brain death as a legal fiction is also necessary to validate informed consent for organ donations. These provisions would be most impactful if adopted nationwide, but change has to start somewhere. Why not in Indiana?

This is a call to Indiana legislators to lead the way in safeguarding the right to life of vulnerable patients who cannot speak up for themselves. This includes patients like Kate who may be fully conscious and wish, more than anything, to

323. Shah, *supra* note 26, at 304.
324. IND. CODE § 34-18-12-3(1) (2025).
325. Shapiro, *supra* note 22, at 165; Schiller, *supra* note 27, at 214.
326. Truog, *supra* note 36, at 1913.
327. Schiller, *supra* note 27, at 215.

be viewed as human.[328] As Dr. Owen has come to realize, the stories of Kate, Juan, and many others are a "haunting reminder of the resiliency of consciousness," a reminder to "reflect anew on the nature of *being*, the meaning of what it means to be alive, and whether *anyone* can be said to be irretrievably lost."[329]

328. OWEN, *supra* note 1, at 39.
329. *Id.* at 215.