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INFORMED CONSENT SHOULD BE REQUIRED BEFORE BRAIN DEATH TESTING

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When at the Department of Motor Vehicles to obtain a driver's license, applicants are asked the question, "Do you wish to be an organ donor?" Many people, wishing to be altruistic, answer yes, without actually understanding what they have agreed to. Because 68 percent of deceased organ donors are declared dead using neurologic criteria,¹ it is appropriate that before becoming an organ donor people be told pertinent medical information about how brain death (BD) is diagnosed—that is, they should be given the chance for informed consent. Informed consent is a cornerstone of medical ethics. It involves communicating the risks, benefits, and alternatives prior to a medical test or procedure.

The basic premise of BD is that when the brain has ceased to function, a person is dead. This concept was introduced in 1968 by an influential Harvard Medical School committee with the oxymoronic definition of "irreversible coma as a new criterion for death."² The obvious contradiction is that to be in a coma is not to be dead, but alive. A corpse is not comatose.

Later, in 1981, an authoritative federal bioethics commission approved the Uniform Determination of Death Act (UDDA), which states that a person with "irreversible cessation of all functions of the entire brain, including the brain stem, is dead."³ This terminology is found in the laws of all fifty states, with slight variations.

Recently, an effort was made to revise the UDDA (rUDDA) to bring the legal definition of death into alignment with how BD is determined in clinical practice. One important proposition in the rUDDA was that informed consent need no longer be required prior to BD testing.⁴ Although the rUDDA effort was suspended indefinitely in September 2023, its proposed changes were adopted in the 2023 consensus guideline for diagnosing BD issued by the American Academy of Neurology, the American Academy of Pediatrics, the Child Neurology Society, and the Society of Critical Care Medicine (hereafter "2023 BD guideline"). Recommendation statement 34 from that guideline reads, "Clinicians do not need to obtain consent before an evaluation for BD/DNC [death by neurologic criteria] unless otherwise stipulated by the institution's policy or state laws or regulations (Level A)."⁵

By explaining global ischemic penumbra and the apnea test, this article will show that the 2023 BD guideline is both unsound (insofar as it does not reliably diagnose BD) and unethical (insofar

as it condones withholding disclosure of medical risks accompanying BD testing).

Global Ischemic Penumbra

In order to better understand the disordered state following severe brain injury, imagine a garden hose watering a bed of roses. When I turn on the spigot, water streams out of the hose, watering the roses and ensuring a healthy rose bed. If I were to park my car directly on the hose, however, the pressure from the car would prevent water from flowing. Without water, the roses would die. But if I moved my car a fraction of an inch so that a trickle of water could reach the roses, they would receive a sufficient amount to survive, albeit without the vibrant blooms expected in a state of robust health.

Let us apply this analogy to BD. The human head has a thick frame of bone called the skull, which after infancy is rigid. Blood vessels, analogous to the garden hose, enter the skull through holes in its base. Normally blood flows freely through these vessels. In the setting of severe brain injury, though, pressure in the skull increases. This progressively compresses the blood vessels in the skull, eventually causing their total collapse (analogous to the car being on top of the garden hose). If the brain's blood supply is completely lost, it dies.

However, if the elevated pressure in the skull is insufficient to completely stop blood flow, then the diminished but persistent blood flow could allow the brain (like the roses) to remain alive, but unable to function normally. This is because the amount of energy (and therefore blood flow) needed for brain tissue to remain alive is less than the amount of energy needed for it to function normally. The medical term for this viable but relatively dormant state of the brain is *ischemic penumbra*. This phenomenon is best known in the context of stroke: the penumbral tissue surrounds the infarcted (dead) brain tissue, and the goal of stroke therapy is to salvage the penumbral tissue. If the whole brain is involved (as in the processes leading to BD), that has been called global ischemic penumbra (GIP).⁶

According to the 2023 BD guideline, BD is a clinical diagnosis based on a state of coma, absence of brainstem reflexes, and lack of spontaneous respiratory drive, as demonstrated by the apnea test.⁷ If this state is judged to be permanent, meaning that brain function will not spontaneously return and no medical attempt will be made to make it return, the patient is diagnosed as brain-dead. According to the guideline, a patient in a state of *temporary* coma, apnea, and brainstem areflexia is alive. The determination of permanence is purely opinion-based, as no evidence exists to determine what observation period is sufficient to guarantee permanence. Thus, being alive or dead can be based on someone's opinion.⁸ The brain need not be completely destroyed—some brain cells may still be alive—but this is considered compatible with a diagnosis of BD so long as there is no demonstrable brain function. Or, to be more precise, no demonstrable brain function that counts according to the guideline,