

**ACCOMPANY THE DYING, COMFORT THE GRIEVING: COUNSELING
CLIENTS ABOUT ORGAN DONATION DECISIONS**

FORTHCOMING 2024

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INTRODUCTION

In *The Art of Dying Well*, a seventeenth century meditation on the end of life, the author urges “those who are preparing to depart from this world” to “put their house in order.”¹ Such planning involves ordering not only one’s financial affairs but also one’s corporeal affairs—arranging for the care and disposition of the body, which includes disposition of organs. While numerous resources are rightfully allocated to advocacy and education to increase donation rates for the benefit of organ recipients in critical need, efforts to prepare and support potential donors and their families are neither as robust nor as effective. As a result, the general public, all of whom are potential organ donors and recipients, risk the possible consequences of ill-informed organ donation decisions: unexpected complications, conflict, and distress to grieving families at the end of life. This article will examine how the legal profession can help to bridge that information gap by preparing and supporting potential donors and their families through the process of making informed organ donation choices.

In hospitals across the country, staff must refer deaths to organ procurement organizations (“OPOs”) and are required to discuss the possibility of organ donation with the family members of the deceased in an effort to combat the organ shortage crisis.² Such requests occur

1 ROBERT BELLARMINE, *The Art of Dying Well*, in SPIRITUAL WRITINGS, 235–321 (John Patrick Donnelly & Roland J. Teske eds., Paulist Press 1989).

2 See 42 U.S.C. § 1320b-8(a)(1)(A)(ii); 42 C.F.R. § 482.45(a)(4) (2001); Emily Steeb, *The Gift of Life: Can the Organ Procurement Philosophies from Spain and Iran Help Eliminate the Organ Shortage in the United States?*, 25 IND. INT’L & COMP. L. REV. 311, 322 (2015) (“Among the various duties allocated to them, OPOs must (1) work closely with organ transplant facilities in specific geographic areas in order to identify potential donors, (2) conduct systematic efforts to acquire all usable organs, (3) arrange for the acquisition and preservation of donated organs under standards consistent with those adopted by OPTN, and (4) equitably allocate such organs. OPOs also attempt to increase public awareness through community outreach. Through procurement coordinators, OPOs are able to reach out to families of recently deceased individuals to discuss the potential of organ donation. OPOs then work closely with the United Network for Organ Sharing (UNOS) to match donor organs to recipients. There are currently fifty-eight OPOs in the United States, each covering a specific geographic region.”); Meredith M. Havekost, *The Waiting Game: How States Can Solve the Organ-Donation Crisis*, 72 VAND. L. REV. 691, 705 (2019); OFF. INSPECTOR GEN., DEP’T OF HEALTH & HUM. SERVS., ORGAN DONOR REGISTRIES: A USEFUL, BUT LIMITED, TOOL 3 (2002), <https://oig.hhs.gov/oei/reports/oei-01-01-00350.pdf> (“Medicare requires hospitals to notify their OPO about all individuals whose death is imminent or who die in the hospital, thus ensuring that virtually all potential donors are referred for consideration.”). See

as a standard practice pursuant to legislative and regulatory guidelines that require every death at a hospital receiving Medicare or Medicaid reimbursement to be accompanied by an active pursuit of the family for the decedent's organs.³ In the United States, OPOs (non-profits that are "responsible for recovering organs from deceased donors for transplantation"⁴) are required to "conduct and participate in systematic efforts, including professional education, to acquire all useable organs from potential donors."⁵ To ensure that every potential organ is identified for possible donation, federal and state legislation, working together require OPOs to "have effective agreements . . . with a substantial majority of the hospitals and other health care entities in its service area which have facilities for organ donations," and require each hospital to notify its designated OPO of every imminent or recent hospital death.⁶ When requesting potential donor families' consent,

also Securing the U.S. Organ Procurement and Transplantation Network Act of 2023, 42 U.S.C. § 274 (requiring competitive bidding for OPTN federal contracts with organizations other than UNOS which, since 1986 had monopolized the OPTN contrast as the sole contractor administering the OPTN); Chris Tachibana, *Ending UNOS's Monopoly Over the U.S. Organ Transplant System*, Penn LDI (May 30, 2023), <https://ldi.upenn.edu/our-work/research-updates/ending-unos-monopoly-over-the-u-s-organ-transplant-system/>.

- 3 See National Organ Transplant Act, 42 U.S.C. §§ 273–74; Linda C. Fentiman, *Organ Donation As National Service: A Proposed Federal Organ Donation Law*, 27 SUFFOLK U. L. REV. 1593, 1597 (1993) ("In response to the organ shortage under a system of voluntary organ donation, in 1986 Congress enacted 'Routine Inquiry' legislation, mandating that all hospitals receiving Medicare or Medicaid reimbursement establish protocols pursuant to which all families of dead or dying potential organ donors will be asked to consider donating the organs of their loved one."); 42 U.S.C. § 1320b-8(a)(1)(A) (1997) (requiring hospitals participating in Medicare and Medicaid to "establish[] written protocols for the identification of potential organ donors that . . . assure that families of potential organ donors are made aware of the option of organ or tissue donation and their option to decline").
- 4 United Nations for Organ Sharing, *Organ Procurement Organizations*, UNOS, [https://unos.org/transplant/opos-increasing-organ-donation/#:~:text=Organ%20Procurement%20Organizations%20\(OPOs\)%20are,their%20assigned%20donation%20service%20area](https://unos.org/transplant/opos-increasing-organ-donation/#:~:text=Organ%20Procurement%20Organizations%20(OPOs)%20are,their%20assigned%20donation%20service%20area) (last visited Jan. 9, 2024).
- 5 42 U.S.C. § 273(b)(3)(B); Alexandra K. Glazier, *The Lung Lawsuit: A Case Study in Organ Allocation Policy and Administrative Law*, 14 J. HEALTH & BIOMEDICAL L. 139, 140 (2018) ("OPOs are nonprofit organizations designated by the Center for Medicare and Medicaid Services ('CMS') to coordinate deceased organ donation for transplantation within a specified geographic area.").
- 6 42 U.S.C. § 273(b)(3)(A) (2023); 42 U.S.C. § 1320b-8(a)(1)(A)(iii) (1997) (requiring hospitals participating in Medicare and Medicaid to "establish[] written protocols for the identification of potential organ donors . . . [and] that such hospital's designated organ procurement agency . . . is notified of potential organ donors."); *see also* 42 C.F.R. § 482.45(a)(1) (2001) (requiring participating

OPOs must ensure that “individual(s) responsible for making the donation decision are informed of their options to donate organs or tissues . . . or to decline to donate.”⁷ For every hospital death, unless the decedent made a known refusal to donate, OPOs are authorized to approach the family to seek the organs of their deceased loved ones.⁸

When approaching the bereaved family to solicit an organ donation, the OPO is to do so with “discretion and sensitivity with respect to the circumstances, views, and beliefs of such families.”⁹ In so doing, the OPO is to weigh the “appropriate timing for approaching the family” and approach them with compassionate understanding.¹⁰ In reality, however, donation requests cannot always be sensitively or appropriately made, given the critical shortage of lifesaving organs and the need to act quickly to preserve organ viability.¹¹ Although OPOs may generally endeavor to be caring and compassionate, research has indicated that in some instances, they can be aggressive and insistent in approaching families.¹² One observer reported that “[t]he OPO or

hospitals to implement policies to “notify, in a timely manner, the OPO or a third party designated by the OPO of individuals whose death is imminent or who have died in the hospital.”).

7 42 C.F.R. § 486.342(a) (2019).

8 See Fentiman, *supra* note 3, at 1597 (stating that after 1986, families of *potential donors*, in hospitals accepting Medicare or Medicaid, would be asked to consider donating).

9 42 U.S.C. § 1320b-8(a)(1)(ii) (1997); 42 C.F.R. § 482.45(a) (2001)

The hospital must have and implement written protocols that:

- (1) Incorporate an agreement with an OPO ... under which it must notify, in a timely manner, the OPO or a third party designated by the OPO of individuals whose death is imminent or who have died in the hospital.

...

- (3) Ensure, in collaboration with the designated OPO, that the family of each potential donor is informed of its options to donate organs, tissues, or eyes or to decline to donate.

10 DEP’T OF HEALTH & HUM. SERVS., CMS Pub 100-07 Z058, CENTERS FOR MEDICARE & MEDICAID SERVICES MANUAL SYSTEM (2014); *see also* 42 C.F.R. § 482.45(a)(4) (2001).

11 John P. Lizza, *Why DCD Donors Are Dead*, 45 J. MED. & PHIL. 42, 43 (2020) (“Successful organ transplantation requires well-preserved organs. In the case of transplantation of vital organs, such as the heart or liver, there is reason to remove the organs as soon after death as possible.”).

12 See Rob Stein, *New Zeal in Organ Procurement Raises Fears*, NBC NEWS (Sept. 13, 2007), <https://www.nbcnews.com/id/wbna20750207>; Robert D. Truog, *Consent for Organ Donation – Balancing Conflicting Ethical Obligations*, 358 N. ENGL. J. MED. 1209, 1210 (2008); Todd Park et al., *The Costly Effects of an Outdated Organ Donation System*, ch. 4., n.20, <https://bloomworks.digital/organandonationreform/OPO-Best-Practices/> (last visited Feb. 13, 2023).

hospital staff will often tell the family that the patient is dead, and then 2 minutes later ask about donation,” while another critical care physician remarked “I have seen these guys come in and almost browbeat families into submission to get them to donate organs.”¹³

In the face of an impending or recent death, and pressured by the need to make a decision quickly, the request for organs can be disturbing for family members, as is evident in the following reflection of a new widow asked to donate her husband’s kidneys shortly after his death:

In my state of acute shock, distress and grief, there suddenly came this totally unexpected question—I was astounded and utterly appalled at such a complete lack of feeling. . . . To make such a decision for oneself is hard enough but to be asked to make it on behalf of another, while one is so shocked and grief-stricken, is both harrowing and cruel. . . . Never could I want any close relative to suffer as I had done in making such an agonizing decision during the worst moment of a life time.¹⁴

At the time the organ donation request is made, the grieving family is contending with the complex emotions that surround a recent or imminent loss.¹⁵ Family members may have not yet had time to process or accept the death. Still coming to terms with their bereavement, and in need of time and space to mourn, the family is asked to grapple with new concerns thrust upon them by the organ donation request that can feel like “an intrusion into the final, intimate moments” of life.¹⁶ The potential donor may still be on a ventilator or other medical equipment to maintain organ function at the time the request for organs is made, and pre- and post-mortem procedures or interventions conducted on the patient, or decedent, to preserve organ viability may be ill-understood or disturbing to families in the midst of trying to emotionally and psychologically process their loss. Indeed, some families recount “traumatic memories of the organ procurement process, reporting that care providers became ‘organ focused’ rather

13 *Id.*

14 Lloyd R. Cohen, *Increasing the Supply of Transplant Organs: The Virtues of a Futures Market*, 58 GEO. WASH. L. REV. 1, 14 (1989).

15 Stephen Doran, *Organ Donation and the Ars Moriendi*, 86 LINACRE Q. 327, 332 (2019).

16 Audiey Kao, *The Physician’s Role in Discussing Organ Donation at the End of Life*, 2 AMA J. ETHICS (2000) (“[T]he appearance of OPO or other designated requestors on the end-of-life scene feels like an intrusion into the final, intimate moments between patient and physician, patient and family members.”).

than ‘person focused.’”¹⁷

Although the patient must be legally declared dead before organ harvesting can occur, advancements in medical technology that prolong organ function can blur the line between life and death and make it difficult for families to accept that the donor is in fact deceased.¹⁸ Adding further complexity, methods for determining death vary between states, and medical professionals continue to disagree about what measures and criteria are to be applied in making the determination that death has occurred. Uncertainty surrounding end of life decisions and organ donation has led to civil actions against hospitals, medical providers, and organ procurement organizations.¹⁹ Such challenges have included, in recent years, objections to medical tests or procedures required for death to be declared and donation to occur, rejection by families of the hospital’s declaration that the patient has died, and refusal by surrogate decision-makers to sanction the decedent’s previously expressed wish to donate after death.²⁰ Resulting contentious end-of-life disputes and highly publicized lawsuits have spurred recent, unsuccessful efforts by the Uniform Law Commission to revise and streamline the medical-legal definition of death, with far-reaching implications for organ donation.²¹ In light of the complexity and controversy surrounding

17 Doran, *supra* note 15, at 328.

18 Sam David Shemie & Dale Gardiner, *Circulatory Arrest, Brain Arrest and Death Determination*, 5 FRONTIERS CARDIOVASC. MED. 1, 1 (2018) (“Technological advances, particularly in the capacity to support, replace or transplant failing organs, continue to challenge and refine our understanding of human death. Discussions about death are complex and deeply sensitive. All human beings die, yet there are philosophical, religious and cultural differences in the concept and definitions of death; and the loss of a loved one has profound emotional, psychological and spiritual impact on family and friends. These opinions are sometimes aired in academia and the media, where the discourse suffers from well-known deficits in understanding and/or awareness of the issues surrounding death determination. A key modern challenge, that is a direct result of technological advances in the fields of resuscitation and transplant medicine, is the unavoidable relationship between death and deceased organ donation.”).

19 See Thaddeus Pope, *Brain Death and the Law: Hard Cases and Legal Challenges*, 48 HASTINGS CTR. REP. S46, S48 (2018) (“Over the past several years, families have filed [brain death] lawsuits in California, Massachusetts, Michigan, Ontario, and Washington, D.C. . . .” and although “the courts have uniformly denied these claims, still more of these disputes are pending adjudication.”).

20 *Id.*; see also Thaddeus Mason Pope, *Brain Death - Injunction Cases*, <https://www.thaddeuspope.com/braindeath/injunctioncases.html> (last visited Jan. 7, 2023) (listing “court cases in which families challenged a brain death diagnosis and obtained extra time in the hospital even though they never proved or prevailed on the underlying claim”).

21 Determination of Death Committee, UNIF. L. COMM’N, <https://www.uniformlaws>.

organ donation, some have questioned the propriety of existing organ donation practices, cautioning that they interfere with the sanctity of the death and grieving process and “overshadow the *ars moriendi*—the art of dying.”²²

Yet families who are prepared for the organ donation decision and who know the donor’s wishes react more positively to the donation process.²³ Preparation for the organ donation decision results in far less family conflict and distress at the end of life when the donation request is made.²⁴ Such families report finding reassurance in knowing and honoring their loved one’s wishes and, where the decedent agreed to donate, the family may experience comfort through their act of lifesaving philanthropy.²⁵

Historically, organ donation has fallen within the realm of estates and trusts law, and recording organ donation decisions remains an important part of any comprehensive estate plan.²⁶ A key goal of estate planning is to relieve the family of the burden of having to make difficult decisions on behalf of the decedent and prevent potential conflict and end of life disputes.²⁷ Through wills that clarify testamentary wishes, advance healthcare directives that appoint a healthcare proxy to make healthcare decisions for an incapacitated person, or living wills specifying treatment preferences and choices, legal professionals endeavor to help clients prepare themselves and their loved ones, in

org/committees/community-home?CommunityKey=a1380d75-62bc-4a5b-ba3a-e74001a9ab57 (last visited Jan. 9, 2024); Robert D. Truog & David C. Magnus, *The Unsuccessful Effort to Revise the Uniform Determination of Death Act*, 330 JAMA 2335, 2335–36 (2023).

22 Doran, *supra* note 15, at 327.

23 See Thomas R. Wojda et al., *Keys to Successful Organ Procurement: An Experience-Based Review of Clinical Practices at a High-Performing Health-Care Organization*, 7 INT’L J. CRIT. ILLNESS & INJURY SCI. 91, 95, 98 (2017).

24 *Id.* at 98.

25 See Doran, *supra* note 15, at 330, 333.

26 Jed Adam Gross, *E Pluribus Unos: The National Organ Transplant Act and Its Postoperative Complications*, 8 YALE J. HEALTH POL’Y, L. & ETHICS 145, 155 (2008); Mercedes Bern-Klug & Elizabeth A. Byram, *Older Adults More Likely to Discuss Advance Care Plans with an Attorney than with a Physician*, 3 GERONTOLOGY AND GERIATRIC MED., NOV. 2017, at 1–5; Sarah Hooper et al., *Improving Medical-Legal Advance Care Planning*, 2, J. PAIN & SYMPTOM MGMT., 487, 488 (2020) (“[P]atients are likely or more likely to engage in ACP with lawyers than with health care providers.”).

27 Grace W. Orsatti, *Attorneys as Healthcare Advocates: The Argument for Attorney-Prepared Advance Healthcare Directives*, 50 J. LAW. MED. ETHICS 157, 157 (2022); PATRICK EMERY LONGAN ET AL., *THE FORMATION OF PROFESSIONAL IDENTITY: THE PATH FROM STUDENT TO LAWYER* (2019) (“Every avoidable conflict that an office lawyer does not foresee or prevent leaves the doors open for later litigation.”).

advance, for the difficult decisions that must be made at, or near, the end of life.²⁸

With respect to organ donation, the legal profession has the potential to play an impactful and beneficial role in bridging the information gap between potential donors and their families, to reduce uncertainty and distress at the end of life. Such meaningful consideration of and preparation for the organ donation question can help to avoid misunderstanding or disagreement at the end of life. This Article will illustrate the manner in which such organ donation disagreements may arise, and how legal professionals can counsel and support clients in advance as they seek to make meaningful organ donation choices. The Article will also reflect on recent efforts to revise the Uniform Determination of Death Act (“UDDA”) to address some of the confusion and conflict surrounding death determination and the potential repercussions on organ donation of such proposed UDDA changes. Finally, given the interdisciplinary nature of end-of-life planning, this Article will explore how medical-legal partnerships can help to inform legal professionals to better prepare individuals to make and record meaningful and informed organ donation choices with the goal of honoring client’s wishes and helping to relieve the burden on families of unanticipated, unknown, or misunderstood organ donation decisions at the end of life.

I. MANNER IN WHICH ORGAN DONATION DECISIONS CAN BE MADE

The organ donation statutes of all fifty states, which permit individuals to declare their organ donation choices in advance, are generally based on the Revised Uniform Anatomical Gift Act (“UAGA”).²⁹

28 Megan S. Wright, *Equality of Autonomy? Physician Aid in Dying and Supported Decision-Making*, 63 ARIZ. L. REV. 157, 162 (2021) (“Advance care planning can include appointing a healthcare agent; completing a living will with written instructions about what an individual wants in the event of various medical scenarios or how others should make decisions on their behalf; discussing one’s wishes or preferences with loved ones; or completing various medical orders such as a Physician’s Order for Life-Sustaining Treatment. Advance care planning is meant to ensure that an individual’s healthcare decision-making autonomy is respected throughout their life, even when they lack decision-making capacity.”).

29 Revised Unif. Anatomical Gift Act § 1 *et. seq.* (UNIF. L. COMM’N 2006); Isa Elfers, *Alienation, Commodification, and Commercialization: A Feminist Critique of Commercial Surrogacy Agreements Through the Lens of Labor Exploitation and U.S. Organ Donation Law*, 33 HASTINGS J. GENDER & L. 151, 155 (2022) (“The primary governing law concerning organ donation in the U.S. is the [UAGA], approved by Congress in 1968 and subsequently adopted by all fifty states and the District of

Although UAGA serves as a model for the individual states' anatomical gift statutes, the language of each state's anatomical gifts act may differ.³⁰ In general, however, state statutes governing organ donation present the public with three options for deciding what will happen to their organs upon death: (A) an individual may authorize donation of their organs, (B) an individual may refuse to donate their organs, or (C) an individual may make no decision about whether or not to donate their organs and leave the decision to others. Each of these decisions has a vastly different outcome at the end of a person's life, not only for the potential donor but also for their surrogate decision-makers and family.

A. *Authorizing Organ Donation*

In the United States, any individual who wishes to donate must “opt in” and affirmatively choose to become a donor. This process by which an individual makes a decision to give their own organs as a gift, known as “first-person authorization,” requires that those who agree to authorize the donation of their organs record or communicate that decision in certain statutorily specified ways.³¹ This first-person authorization requirement, with its emphasis on personal autonomy, stands in contrast to “opt-out” paradigms that exists in countries such as the United Kingdom in which every individual is presumed to have consented to donation, and must record a decision to “opt out” if they

Columbia.”).

30 Elfers, *supra* note 29, at 155–56.

31 Laura A. Siminoff et al., *Consent to Organ Donation: A Review*, 23 *PROGRESS IN TRANSPLANTATION* 99, 99 (2013).

Currently, all 50 states and the District of Columbia have first-person authorization laws, which recognize the primacy of the deceased's documented desire to become a posthumous organ donor. These laws permit organ donation without family consent if the deceased has designated him/herself as a donor on a driver's license, donor card, or a donor registry. First-person authorization addresses concerns that pursuing organ retrieval without family consent could result in legal action. The policy is a guarantor of patient autonomy and the legal authority of OPOs and hospitals to uphold individuals' documented donation wishes. By prioritizing the deceased's wishes, first-person authorization also circumvents discrepancies between the deceased's and families' organ donation preferences and provides assurances to the family of the deceased's wishes at a time of uncertainty and great emotional distress.

Id.; see also Alexandra K. Glazier, *Organ Donation and the Principles of Gift Law*, 13 *CLINICAL J. AM. SOC'Y NEPHROLOGY* 1283, 1283 (2018).

choose not to participate.³²

For those in the United States who choose to “opt in” and become donors, state statutes provide various methods by which to authorize such a gift. To increase the ease and facility of donation, individuals can record their decision online with an approved donor registry, on an organ donor card, or by having an organ donor designation displayed on a driver’s license or identification card.³³ Organ donation registries, organ donor cards, or organ donor designations on a state issued license or identification card are the methods the public is most familiar with for recording an organ donation choice.³⁴ These methods of recording

32 Douglas MacKay, *Opt-out and Consent*, 41 J. MED. ETHICS 832, 832 (2015) (“Opt-in policies, which require people to actively register as organ donors, are often thought to better respect people’s autonomy than opt-out policies since they aim to secure people’s actual consent to organ retrieval.”).

33 Revised Unif. Anatomical Gift Act § 5 (UNIF. L. COMM’N 2006). The act provides:

- (a) A donor may make an anatomical gift:
 - (1) by authorizing a statement or symbol indicating that the donor has made an anatomical gift to be imprinted on the donor’s driver’s license or identification card;
 - (2) in a will;
 - (3) during a terminal illness or injury of the donor, by any form of communication addressed to at least two adults, at least one of whom is a disinterested witness; or
 - (4) as provided in subsection (b).
- (b) A donor or other person authorized to make an anatomical gift under Section 4 may make a gift by a donor card or other record signed by the donor or other person making the gift or by authorizing that a statement or symbol indicating that the donor has made an anatomical gift be included on a donor registry. If the donor or other person is physically unable to sign a record, the record may be signed by another individual at the direction of the donor or other person and must:
 - (1) be witnessed by at least two adults, at least one of whom is a disinterested witness, who have signed at the request of the donor or the other person; and
 - (2) state that it has been signed and witnessed as provided in paragraph (1).
- (c) Revocation, suspension, expiration, or cancellation of a driver’s license or identification card upon which an anatomical gift is indicated does not invalidate the gift.
- (d) An anatomical gift made by will takes effect upon the donor’s death whether or not the will is probated. Invalidation of the will after the donor’s death does not invalidate the gift.

Id.

34 J. Daryl Thornton et al., *Evaluating the Performance of Driver’s License Agencies Using a Standardized Donor Ratio*, 53 TRANSPLANTATION PROC., 555, 556 (2021) (“Department of Motor Vehicles (DMVs) facilities are integral to organ transplantation as they are locations where most Americans consider registering to become organ

organ donation decisions are expedient, uncomplicated, and often do not require potentially obstructive legal formalities such as witnesses or a notary.³⁵ Moreover, decisions recorded through organ donor registries make it easy for medical providers and OPOs to quickly and efficiently access centralized databases to determine whether a deceased individual is an organ donor.³⁶

Although easy and expedient, some critics argue that organ donation decisions made at a location that issues driver's licenses, such as a registry of motor vehicles, or through an online organ donation registry may not adequately prepare donors and their families.³⁷ There is no prerequisite that the donor possess sufficient mental capacity to make such a decision, or that the donor be provided sufficient information to

donors.”).

35 See, e.g., CAL. VEH. CODE § 12811.3(a) (West 2023) (“A written or electronic application for an original or renewal driver’s license or identification card shall contain a space for the applicant to enroll in the Donate Life California Organ and Tissue Donor Registry. The application shall include check boxes for an applicant to mark either (A) Yes, add my name to the donor registry or (B) I do not wish to register at this time.”); MO. REV. STAT. § 194.225 (West 2023) (“A donor may make an anatomical gift: (1) By authorizing a statement or symbol indicating that the donor has made an anatomical gift to be imprinted on the face of the donor’s driver’s license or identification card, or by placing a donor symbol sticker authorized and issued by the department of health and senior services on the back of the donor’s driver’s license or identification card indicating that the donor has made an anatomical gift”); 20 PA. CONS. STAT. § 8619(a) (West 2023) (“The Department of Transportation shall redesign the driver’s license and identification card application system to process requests for information regarding consent of the individual to organ or tissue donation. The following question shall be asked on both the application for a driver’s license or identification card and on the organ donor designation at a photo center: Pennsylvania strongly supports organ and tissue donation because of its life-saving and life-enhancing opportunities. Do you wish to have the organ donor designation printed on your driver’s license? Only an affirmative response of an individual shall be noted on the front of the driver’s license or identification card and shall clearly indicate the individual’s intent to donate his organs or tissue.”).

36 See generally Ana S. Iltis, *Organ Donation, Brain Death and the Family: Valid Informed Consent*, 43 J. LAW, MED. & ETHICS 369 (2015) (discussing the potential shortcomings of driver’s license consents to organ donation, absent informed consent).

37 *Id.*; Truog, *supra* note 12, at 1211; Greg Moorlock & Heather Draper, *A Proposal to Support Making Decisions About the Organ Donation Process*, 49 J. MED. & ETHICS, June 2023, at 2 (“Maintaining simplicity in an organ donation system is generally desirable, insofar as presenting the public with numerous complex options may deter them from making decisions, or potentially create confusion and an unwillingness to donate. But this mismatch between the simplicity of the donation registration system and complexity of donation processes has ethical implications.”).

fully appreciate the potential consequences, risks, and benefits of the decision.³⁸ Nevertheless, designations on driver's licenses and organ donation registries continue to serve as popular and convenient means for recording a donation choice.³⁹

In addition to driver's license designations, donor registries, and donor cards, state statutes generally permit organ donation decisions to be made orally under certain defined conditions. An oral organ donation decision can be made, for example, if an individual who is terminally ill or injured orally communicates their organ donation choice to at least two adults, including one disinterested witness.⁴⁰ Some state statutes require that the oral organ donation decision be memorialized in a signed and dated writing by the witness.⁴¹ This allows for organ donation decisions to be made in an emergency or near the end of life.

In addition to the foregoing methods of memorializing an organ donation choice, some state statutes provide that organ donation decisions may be recorded in estate planning documents such as a last will and testament or advance healthcare directive.⁴² When organ donation decisions are recorded as part of an estate plan, additional legal formalities, such as witnesses and a notary, help to ensure the validity and authenticity of the documented decisions. However, such formalities may make this method of recording organ donation decisions more cumbersome than simply using a donor registry or driver's license designation.⁴³ Moreover, such paperwork is often lost, misplaced, or otherwise inaccessible, or found too late for the organ

38 See generally Moorlock & Draper, *supra* note 37.

39 Thornton et al., *supra* note 34, at 555, 556.

40 See, e.g., ALASKA STAT. § 13.52.177 (West 2023); ARIZ. REV. STAT. § 36-844 (2023); Revised Unif. Anatomical Gift Act § 5 (UNIF. L. COMM'N 2006).

41 See, e.g., CAL. HEALTH & SAFETY CODE § 7150.20(a)(4).

42 See, e.g., ME. REV. STAT. ANN. tit. 22, § 2945 (West 2023); MASS. GEN. LAWS ANN. ch. 113A, § 5 (2023).

43 The comments to the Uniform Anatomical Gift Act note:

Typically an anatomical gift of a part for transplantation or therapy is not made by a will. In fact, donors are ill-advised to make an anatomical gift by will as the terms of the will may not be known in sufficient time to allow for successful recovery of the gifted parts. Individuals who make an anatomical gift of their parts in a will for transplantation or therapy should make their wishes known by other means as well. On the other hand, some individuals donate their bodies to medical science for research or education, and they may do so by a will.

Revised Unif. Anatomical Gift Act § 5. cmt. (UNIF. L. COMM'N 2006).

donation provisions to take effect.⁴⁴ Therefore, when organ donation decisions are memorialized in a will or advance directive, it is imperative to ensure that the document is available to all interested parties, when needed. This can be done by instructing the client to share the document with their agent and family, or doing so on the client's behalf, and directly providing a copy of the document to the client's physician or medical records department.⁴⁵ Directly providing advance directive documents to family, a healthcare agent (a proxy decision-maker), and healthcare providers may be especially useful for clients facing imminent hospitalization or admission to a nursing home or other healthcare facility, ensuring that their wishes are known and available.⁴⁶ Providing a copy of the will or advance healthcare directive directly to the client's hospital or medical records office, or advising the client to do so on their own, increases the probability that such documents are available when needed, and that families are aware of and prepared for the organ donation decision to reduce the likelihood of surprise, disagreement, or family conflict at the end of life.

When organ donation decisions are included in documents executed as part of an estate plan, an assessment of the client's capacity is generally required. Although there is no defined measure for determining the capacity required to donate organs, where such decisions are part of a will or advance healthcare directive, the client must demonstrate to counsel that they possess sufficient capacity to

44 Peiyuan Zhang & John G. Cagle, *When Living Wills Go Missing: Associations with Hospice Use and Hospital Death Using National Longitudinal Data*, 42 J. APPLIED GERONTOLOGY, 1108, 1108–12 (2023).

45 *Id.* (“nearly a fifth (21.5%) of American older adults age 65+ had [a living will] that went missing . . . it is advisable to encourage patients with completed [living wills] to store them in easy-to-find locations that are known and accessible to family decision-makers and/or healthcare providers”); Corita R. Grudzen et al., *Concordance of Advance Care Plans with Inpatient Directives in the Electronic Medical Record for Older Patients Admitted From the Emergency Department*, 51 J. PAIN & SYMPTOM MGMT. 647, 650 (2016) (“About half of the patients 65 years or older arriving in the ED have done significant advance care planning. However, most plans are not being recorded in the EMR when such patients are admitted.”).

46 Revised Unif. Anatomical Gift Act § 5 cmts. (UNIF. L. COMM’N 2006) (“Individuals who make an anatomical gift of their parts in a will for transplantation or therapy should make their wishes known by other means as well.”). State statutes may specifically provide that a written organ donation decision be “deposited in any hospital, bank or storage facility that accepts it for safekeeping or for facilitation of procedures after death.” 20 PA. CONS. STAT. § 8614 (West 2023). Where the donation decision is recorded through multiple means, however, care should be taken to ensure that all documents are consistent, to avoid conflicting organ donation wishes.

execute the underlying document, necessitating at the very least a showing that the client understands the nature of their actions and the effects thereof.⁴⁷

It is important to note, however, that the capacity required to prepare estate planning and advance directive documents does not equate to informed consent to any medical procedures that may be required in order for organ donation to occur. Such assessments of informed consent do not occur within the context of the lawyer-client relationship but properly belong in the physician-patient realm.⁴⁸ Informed consent demands that “the individual must have the opportunity to evaluate all options knowledgeably and to understand the risks of each available option.”⁴⁹ While informed consent may be required for healthcare and medical treatment decisions generally, “the law clearly views deceased organ donation as anatomical gifting and not as a healthcare decision for the donor.”⁵⁰ This discrepancy can result in a mismatch between the donor’s understanding of their donation decision and the medical consequences of that decision, of which the

47 See, e.g., UNIF. PROB. CODE § 2-501 (UNIF. L. COMM’N 2020) (“An individual 18 or more years of age who is of sound mind may make a will”); RESTATEMENT (THIRD) OF PROPERTY § 8.1 (AM. L. INST. 2003) (“(a) A person must have mental capacity in order to make or revoke a donative transfer. (b) If the donative transfer is in the form of a will, a revocable will substitute, or a revocable gift, the testator or donor must be capable of knowing and understanding in a general way the nature and extent of his or her property, the natural objects of his or her bounty, and the disposition that he or she is making of that property, and must also be capable of relating these elements to one another and forming an orderly desire regarding the disposition of the property. (c) If the donative transfer is in the form of an irrevocable gift, the donor must have the mental capacity necessary to make or revoke a will and must also be capable of understanding the effect that the gift may have on the future financial security of the donor and of anyone who may be dependent on the donor”); UNIF. HEALTHCARE DECISIONS ACT § 1 (UNIF. L. COMM’N 1993) (defining capacity make health decisions as the “ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision.”); see also UNIFORM HEALTHCARE DECISIONS ACT § 3 (UNIF. L. COMM’N 2023).

48 See Hayley Cotter, *Increasing Consent for Organ Donation: Mandated Choice, Individual Autonomy, and Informed Consent*, 21 HEALTH MATRIX 599, 605 (2011).

49 *Id.* at 605–06.

50 Alexandra K. Glazier, *The Principles of Gift Law and the Regulation of Organ Donation: Principles of Gift Law*, 24 TRANSPLANT INT’L 368, 369 (2011) (“The informed consent doctrine fundamentally requires the consenting party make a decision regarding a proposed healthcare treatment or procedure through a facilitated understanding of the attendant risks and benefits. There are, however, neither risks not benefits to a deceased donor from donation.”); see also Revised Unif. Anatomical Gift Act § II (UNIF. L. COMM’N 2006).

donor may be unaware given that organ donation, which is premised on and governed by principles of gift law rather than informed consent, requires only that the giver demonstrate “donative intent,” which means simply that the donor has formed an affirmative objective to donate.⁵¹

B. *Refusal to Donate*

Those who refuse to donate their organs are generally required to record their refusal in certain specified ways. UAGA provides that refusal to donate may be made in a signed record, in a last will and testament, or, in the event of terminal illness or injury, orally in the presence of a disinterested witness.⁵² Once an individual refuses to donate, no one can override that decision.⁵³ If the decedent’s refusal to donate is known, no other individual can make a gift of that individual’s body or part, and receipt or acceptance of organs from that decedent is prohibited.⁵⁴

C. *Failure to Authorize or Refuse Donation*

Abstaining from making a decision to donate organs (that is, neither authorizing nor refusing to donate) does not necessarily preclude organs from being donated.⁵⁵ Individuals who opt not to

51 Glazier, *supra* note 31, at 1283–84 (Gifts of any type must fulfil three basic elements to be legally recognized: (i) there must be donative intent; (ii) the gift must be physically transferred or delivered; and (iii) the gift must be accepted.); Megan S. Wright, *Resuscitating Consent*, 63 B.C. L. REV. 887, 900 (2022) (“Both law and medical ethics require physicians to obtain informed consent from patients prior to providing medical treatment; however, a significant body of research has demonstrated that the ideal of informed consent rarely matches the reality of healthcare decision making.”).

52 Revised Unif. Anatomical Gift Act § 7 cmt. (UNIF. L. COMM’N 2006).

53 *Id.* (“Except as otherwise provided in Section 8(h), in the absence of an express, contrary indication by the individual set forth in the refusal, an individual’s unrevoked refusal to make an anatomical gift of the individual’s body or part bars all other persons from making an anatomical gift of the individual’s body or part.”).

54 *See, e.g.*, OR. REV. STAT. § 97.961 (West 2023); OR. REV. STAT. § 97.969 (West 2023); MD. CODE ANN., EST. & TRUSTS § 4-505 (West 2023).

55 *See, e.g.*, N.Y. PUB. HEALTH LAW § 4310 (5)(b)(ii) (McKinney 2023) (indicating that for those who opt out of organ donation at the time of driver’s license registration, that decision “shall not be construed to imply a wish not to donate.”); 20 PA. CONS. STAT. § 8619 (West 2023) (“Only an affirmative response of an individual shall be noted on the front of the driver’s license or identification card and shall clearly indicate the individual’s intent to donate his organs or tissue”); 20 PA. CONS. STAT.

document their authorization or refusal to donate are cautioned that it remains possible that their organs may be donated nevertheless. Simply declining to list that one is a donor when obtaining a driver's license, for example, may not equate to refusal to donate. Rather, for individuals whose organ donation wishes are unknown, the decision as to whether or not their organs will be donated may be ceded instead to a third party, such as the decedent's healthcare agent, family, or other responsible party.⁵⁶

II. FEDERAL AND STATE REGULATION OF ORGAN PROCUREMENT

The authority given to family members, healthcare agents, or other surrogates to authorize or refuse organ donation on behalf of a decedent has been standardized and regulated through federal and state legislation, which work together to support a national organ donation network of systems. This federal and state regulatory framework, described in greater detail below, ensures that hospitals and organ procurement organizations across the country work closely together to achieve "maximum effectiveness in the procurement and equitable distribution of organs."⁵⁷

A. *National Organ Transplant Act of 1984*

In 1984, Congress enacted the National Organ Transplant Act ("NOTA") to regulate organ donation.⁵⁸ NOTA, along with related federal regulations, standardizes organ procurement and allocation nationwide. Through NOTA, Congress authorized the creation of the Organ Procurement and Transplantation Network ("OPTN").⁵⁹ OPTN centralizes and streamlines organ donation and organ allocation by

§ 8617 (West 2023) (authorizing the organ procurement organization to inform family, or other representative of the decedent, of the option to donate the decedent's organs and tissues).

56 Hilary Young, *The Right to Posthumous Bodily Integrity and Implications of Whose Right It Is*, 14 MARQ. ELDER'S ADVISOR 197, 235, 248 (2013) ("Although refusal is presumed, where the deceased did not consent or refuse in a legally recognized manner, family members, in a hierarchy set out by the UAGA, may decide whether to donate their relative's organs.").

57 42 U.S.C. § 273; *Ramirez v. Health Partners of S. Ariz.*, 972 P.2d 658, 661 n.7 (Ariz. Ct. App. 1998) ("[O]rgan donation is a matter of both state and federal law.").

58 National Organ Transplant Act ("NOTA"), Pub. L. No. 98-507, 98 Stat. 2339 (1984).

59 Neal R. Barshes et al., *Justice, Administrative Law, and the Transplant Clinician: The Ethical and Legislative Basis of a National Policy on Donor Liver Allocation*, 23 J. CONTEMP. HEALTH L. & POL'Y 200, 209-12, 218-19 (2007).

maintaining a list of individuals in need of organs and establishing a system to match organs with those individuals.⁶⁰ OPTN comprises all U.S. transplant centers as well as OPOs, which operate regionally to identify potential donors in their geographic area.⁶¹ This allows for efficient, well-regulated organ procurement and distribution nationwide.

B. Organ Procurement Organizations

OPOs work together with hospitals and healthcare entities to identify potential organ donors within the OPO's service area.⁶²

60 See *id.* at 217–18.

61 42 U.S.C. § 274(b)(2)(A)(ii).

62 *Id.* § 273(b)(3). The statute provides:

(3) An organ procurement organization shall—

(A) have effective agreements, to identify potential organ donors, with a substantial majority of the hospitals and other health care entities in its service area which have facilities for organ donations,

(B) conduct and participate in systematic efforts, including professional education, to acquire all useable organs from potential donors,

(C) arrange for the acquisition and preservation of donated organs and provide quality standards for the acquisition of organs which are consistent with the standards adopted by the Organ Procurement and Transplantation Network under section 274(b)(2)(E) of this title, including arranging for testing with respect to identifying organs that are infected with human immunodeficiency virus (HIV),

(D) arrange for the appropriate tissue typing of donated organs,

(E) have a system to allocate donated organs equitably among transplant patients according to established medical criteria,

(F) provide or arrange for the transportation of donated organs to transplant centers,

(G) have arrangements to coordinate its activities with transplant centers in its service area,

(H) participate in the Organ Procurement Transplantation Network established under section 274 of this title,

(I) have arrangements to cooperate with tissue banks for the retrieval, processing, preservation, storage, and distribution of tissues as may be appropriate to assure that all useable tissues are obtained from potential donors,

(J) evaluate annually the effectiveness of the organization in acquiring potentially available organs, and

(K) assist hospitals in establishing and implementing protocols for making routine inquiries about organ donations by potential donors.

Id. See also Havekost, *supra* note 2, at 694–95 (“OPOs are regional, private nonprofit organizations incorporated under state law that work with organ-transplant facilities and qualifying hospitals to arrange for the acquisition and preservation of donated organs and allocate them to patients on the waiting list.”); Alison Shea, *Harvesting Hope: Regulating and Incentivizing Organ Donation*, 52

By entering into agreements with area hospitals and other similar facilities, OPOs around the country can efficiently identify patients at or near death who may be potential organ donors. Upon identifying such potential donors, OPOs then must systematically “arrange for the acquisition and preservation of donated organs.”⁶³

To ensure efficiency in the organ acquisition process, federal regulations require Medicare- and Medicaid-eligible hospitals to establish an agreement with a regional OPO to be eligible for federal funding.⁶⁴ In accordance with such agreements, participating hospitals must notify their regional OPO of any individuals “whose death is imminent or who have died in the hospital.”⁶⁵ This structure seeks to increase the availability of organs to address the critical organ shortage that causes devastating loss of life.⁶⁶ Hospitals are required to alert OPOs of all deaths regardless of whether the patient has agreed or refused to be an organ donor, or whether their organ donation wishes are unknown.⁶⁷ In fact, OPOs may be alerted by the hospital about the potential for

NEW ENG. L. REV. 215, 222 (2018).

63 42 U.S.C. § 273(b)(3)(c). The statute provides:

An organ procurement organization shall—

(C) arrange for the acquisition and preservation of donated organs and provide quality standards for the acquisition of organs which are consistent with the standards adopted by the Organ Procurement and Transplantation Network

Id.

64 See 42 C.F.R. § 482.45(a) (2023); see also 42 U.S.C. § 273(b)(3)(A)–(B). NOTA provides:

An organ procurement organization shall—

...

(A) have effective agreements, to identify potential organ donors, with a substantial majority of the hospitals and other health care entities in its service area which have facilities for organ donations, conduct and participate in systematic efforts, including professional education, to acquire all useable organs from potential donors[.]

42 U.S.C. § 273(b)(3)(A).

65 42 C.F.R. § 482.45(a)(1) (2023); see also 42 C.F.R. § 486.324(b)(12) (2023) ([T]o expedite the organ donation process, OPOs are required to “[a]ssist[] . . . hospitals in establishing and implementing protocols for making routine inquiries about organ donations by potential donors.”).

66 See Health Res. & Sers. Admin., *Organ Donation Statistics* (Oct. 2023), <https://www.organdonor.gov/learn/organ-donation-statistics>.

67 Identification of Potential Organ, Tissue, and Eye Donors and Transplant Hospitals’ Provision of Transplant-Related Data, 42 C.F.R. § 482.45 (2023) (requiring hospitals to “notify, in a timely manner, the OPO or a third party designated by the OPO of individuals whose death is imminent of who have died in the hospital”).

organ procurement even before the patient's family is aware that such a referral is being made.⁶⁸

*Once the OPO is alerted about a recent or imminent death, if the patient previously agreed to donate, an OPO representative is authorized to approach the decedent's family to inform them that the decedent authorized donation of organs.*⁶⁹ Where the organ donation wishes of the patient are unknown, the OPO may actively approach the surviving family in pursuit of the decedent's organs.⁷⁰ Every decedent who did not previously refuse to donate is a prospective donor whose family may be asked for organs.⁷¹ Families can thus expect to be approached and either informed of the option to make an anatomical gift or expressly asked to authorize organ harvesting, depending on how aggressively OPOs and

68 HEALTH RES. & SERVS. ADMIN., U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES RECOMMENDATIONS 29-35 (June 2021), <https://www.hrsa.gov/advisory-committees/organ-transplantation/recommendations/29-35>.

Whenever possible, referral should be made early enough to allow the OPO to assess the patient's suitability for organ donation before brain death is declared and before the option of organ donation is presented to the family of the potential donor. Timely assessment of the patient's suitability for organ donation increases the likelihood that the patient's organs will be viable for transplantation (assuming there is no disease process identified by the OPO that would cause the organs to be unsuitable), assures that the family is approached only if the patient is medically suitable for organ donation, and assures that an OPO representative is available to collaborate with the hospital staff in discussing donation with the family.

Id. See also Douglas W. Hanto, *Clinical Cases: Family Disagreement over Organ Donation*, 7 ETHICS J. AM. MED. ASS'N 581, 581 (2005), https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-07/ccas2-0509_4.pdf.

69 42 C.F.R. § 482.45(a)(3) (2023) ("The hospital must have and implement written protocols that . . . [e]nsure, in collaboration with the designated OPO, that the family of each potential donor is informed of its options to donate organs, tissues, or eyes or to decline to donate. The individual designated by the hospital to initiate the request to the family must be an organ procurement representative or a designated requestor."); Melissa N. Kurnit, *Organ Donation in the United States: Can We Learn from Successes Abroad?*, 17 B.C. INT'L & COMP. L. REV. 405, 412 (1994) (federal laws and regulations ensure that hospitals cooperate with the requirement to at least inform the family of its opportunity to make an anatomical gift, and hospitals that do not comply risk losing federal aid).

70 See 42 C.F.R. § 486.342 (2023); see also Kurnit, *supra* note 69, at 412–15.

71 See, e.g., KAN. STAT. ANN. § 65-3221 (West 2022) (a "[p]rospective donor" means an individual who is dead or near death and has been determined by a procurement organization to have a part that could be medically suitable for transplantation, therapy, research, or education. The term does not include an individual who has made a refusal."); 20 PA. CONS. STAT. § 8617(c) (2023).

state law permit pursuit of donation.⁷²

C. Surrogate Decision-Making

In deciding who has authority to donate the decedent's organs—if the decedent did not previously authorize or refuse donation—state statutes generally create a default hierarchy of designated family members who are granted such decision-making power, and who will be approached for authorization.⁷³ High priority may be given to the decedent's appointed healthcare agent whom the decedent, when alive, authorized under a healthcare power of attorney to make anatomical gifts on the decedent's behalf.⁷⁴ Absent a healthcare agent, various other family members may make the decision about whether to donate their loved one's organs.⁷⁵ Generally, the decedent's spouse is given priority, then adult children, followed by the decedent's parents. Some states, after spouse, children, or parent, grant priority to the decedent's domestic partner over adult siblings, followed by adult grandchildren then grandparents.⁷⁶ If no such individuals are able to authorize or refuse organ donation, any adult who has exhibited special care and concern for the decedent may be asked to make the decision. The

72 Kurnit, *supra* note 69, at 413 (“Required request laws vary greatly from state to state. The strongest laws require hospitals to request donation and document the approval or refusal on the death certificate. The weaker laws merely require that hospitals develop protocols to ensure that families are apprised of their option to donate. State laws vary as to whether hospitals are required merely to inform of the option to donate, or actually request donation.”); 42 C.F.R. § 482.45(a)(3) (2023); Jonathan G. August, *Modern Models of Organ Donation: Challenging Increases of Federal Power to Save Lives*, 40 HASTINGS CONST. L.Q. 393, 395–96 (2013); Frederick J. White III & J. Kelly Elrod, *Organ Donation After Cardiac Death: A Louisiana Hospital Ethics Committee Perspective*, 39 S.U. L. REV. 71, 91–95 (2011); Kathleen S. Andersen & Daniel M. Fox, *The Impact of Routine Inquiry Laws on Organ Donation*, 7 HEALTH AFFAIRS, no. 5, 1988.

73 See, e.g., IDAHO CODE ANN. § 39-3409 (West 2007); ARK. CODE ANN. § 20-17-1209 (West 2020); 20 PA. CONS. STAT. § 8611 (West 2018); Who May Make Anatomical Gift of Decedent's Body or Part, Revised Unif. Anatomical Gift Act § 9 (UNIF. L. COMM'N 2006).

74 Who May Make Anatomical Gift of Decedent's Body or Part, Revised Unif. Anatomical Gift Act § 9 (UNIF. L. COMM'N 2006); see also Unif. Health-Care Decisions Act § 1, (UNIF. L. COMM'N 1993) (“Agent” means an individual designated in a power of attorney for health care to make a health-care decision for the individual granting the power”) superseded by Uniform Health-Care Decisions Act (UNIF. L. COMM'N 2023).

75 Uniform Health-Care Decisions Act § 12 (UNIF. L. COMM'N 2023).

76 See, e.g., ARIZ. REV. STAT. § 36-848 (West 2007).

person acting as guardian of the decedent prior to their death may also be asked to authorize.⁷⁷ Ultimately, where none of the foregoing persons are available, any other person with authority over disposition of the decedent's body may make the decision if no individual of higher priority is able or willing to decide.

Individuals who do not make or communicate their organ donation wishes risk having that decision ultimately fall on a person whom the decedent might not have wanted to burden with the choice. Parents who do not make a choice, for example, may unintentionally saddle their children with the difficult decision about whether or which of their mother or father's organs to donate. Unforeseen circumstances may result in family members highest on the list of surrogate decision-makers being unsuited to decide, particularly if, for example, that family member has become estranged from the decedent, has no knowledge of the wishes or preferences of the decedent, or has personal views that differ from those of the decedent. Thus, absent appropriate documentation of one's own organ donation decisions, individuals risk having their organ donation preferences misunderstood, misapplied, or dishonored.

Surrogate decision-makers (healthcare agents, guardians, family members, etc.) wield enormous influence over organ donation decisions both before death and after death. Before death is determined, certain pre-mortem procedures may be required to assess the suitability of organs for donation or maintain the organs to keep them viable for transplant.⁷⁸ Surrogate decision-makers are sometimes required to authorize such procedures, and refusal to do so can preclude donation.⁷⁹ In addition, surrogates may be called upon to make decisions about whether and which life-prolonging procedures the patient will receive before

77 See, e.g., IDAHO CODE ANN. § 39-3409 (West 2007).

78 "[T]here are certain pre-mortem (and post-mortem) interventions that can optimize donation. . . . These interventions are not for the direct medical benefit of the patient but are intended to ensure that organs are of optimal quality for transplantation. Relatives might object to such interventions even if they pose little risk of discomfort for the patient, and the potential donor is likely to have been unaware of such interventions when they registered as organ donor." David M. Shaw, *The Consequences of Vagueness in Consent to Organ Donation*, 31 *Bioethics*, 424, 424–431 (2016); Cynthia J. Gries et al., *An Official American Thoracic Society/International Society for Heart and Lung Transplantation/Society of Critical Care Medicine/Association of Organ and Procurement Organizations/United Network of Organ Sharing Statement: Ethical and Policy Considerations in Organ Donation After Circulatory Determination of Death*, 188 AM. J. RESPIRATORY CRITICAL CARE MED. 103, 103 (2013).

79 *Id.* at 106–07.

death, which can affect organ suitability for donation.⁸⁰ Finally, upon a declaration of death, the surrogate's acceptance or rejection of such a death declaration can impact the ability to harvest organs. This can be particularly contentious in instances where the patient is declared brain dead, given ongoing uncertainty in the medical and legal community about the criteria necessary to make a brain death determination.⁸¹ Even where the patient authorized donation, surrogates may be able to prevent donation by exercising what is known as the "family veto" in an effort to override the decedent's donation choice.⁸² This family veto may be exercised for myriad reasons, which may include dissatisfaction with the medical care received by the patient prior to death, uncertainty about whether the decedent truly intended to donate, or differences in organ donation beliefs. Given surrogates' immense authority over the decisions about whether and which organs to donate, surrogate receptivity to or resistance against organ donation directly impacts the availability of organs for those in need.

III. CONTROVERSIES AND CONFLICTS IN DEATH DETERMINATION AND ORGAN DONATION

Much of the resistance to and conflict surrounding organ donation arises from uncertainty about whether the organ removal will cause the donor's death. Longstanding ethical norms require that the organ donor must be dead before organ harvesting may begin.⁸³ In practice, however, death determination is complex and highly nuanced,

80 See generally *id.*

81 Robert D. Truog, *The Uncertain Future of the Determination of Brain Death*, 329 JAMA 971, 971 (2023).

82 Havekost, *supra* note 2, at 691 ("Every state currently allows individuals to unilaterally indicate their intent to donate their organs upon death, but in practice, family members are frequently allowed to override the express intentions of decedents.").

83 This is known as the Dead Donor Rule. See, e.g., John A. Robertson, *The Dead Donor Rule*, 29 HASTINGS CTR. REP. 6 (1999) (defining the dead donor rule as "the ethical and legal rule that requires that donors not be killed in order to obtain their organs."); see also 40 LA. STAT. ANN. § 1061.25 (West 2022) ("The protocol known commonly as the 'dead donor rule' is a longstanding ethical norm that protects the integrity of human organ donation by providing that organ donors must be dead before procurement of organs begins, and that organ procurement itself must not cause the death of the donor."); FRANKLIN G. MILLER & ROBERT D. TRUOG, *DEATH, DYING, AND ORGAN TRANSPLANTATION: RECONSTRUCTING MEDICAL ETHICS AT THE END OF LIFE* 115 (2016) ("The Dead Donor Rule is seen as protection against exploitation. No person should be sacrificed and treated merely as a means for obtaining vital organs to save the lives of others.").

particularly in light of life-saving and life-prolonging advancements in medical technology and transplantation science that can make the precise moment of death difficult to ascertain. Medical science lacks precision as to exactly when death occurs, and the resulting debates over how and when death should be determined can form the basis of many organ donation disputes and resulting litigation.

In an effort to provide clarity, the Uniform Determination of Death Act (“UDDA”) promulgated by the Uniform Law Commission in 1980, as model legislation for the states, defines death as follows: “An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.”

Thus, pursuant to the UDDA, an individual may be declared dead in two ways: (1) “circulatory-respiratory death” and (2) “brain death” or “death by neurologic criteria.”⁸⁴ Only after a determination of either circulatory-respiratory death or brain death has been made “in accordance with accepted medical standards,” can organs be harvested from the deceased person.⁸⁵

A. *Brain Death and Organ Donation: Concerns and Controversies*

Of the two methods for declaring death, the concept of “brain death” is relatively new and highly controversial. “The majority of organs transplanted are recovered from patients who died by neurological criteria or brain death,” so how we determine brain death necessarily affects the availability of organs for transplant.⁸⁶ Historically, and prior to modern innovations in medical technology, a lack of a heartbeat or ability to breathe caused loss of brain function and ensuing failure of all other organs, resulting in death. Modern medical practices, however,

84 See, e.g., James L. Bernat, *Challenges to Brain Death in Revising the Uniform Determination of Death Act: The UDDA Revision Series*, 101 *NEUROLOGY* 30 (2023).

85 See Unif. Determination of Death Act § 1 (UNIF. L. COMM’N 1980).

86 Mohammed F. Kananeh et al., *Factors That Affect Consent Rate for Organ Donation After Brain Death: A 12-Year Registry*, 415 *J. NEUROLOGICAL SCI.*, Sept. 2020, at 1, 5; see also David M. Greer et al., *Variability of Brain Death Policies in the United States*, 73 *J. AM. MED. ASS’N NEUROLOGY* 213, 217 (2016) (noting that “significant variability in the number of examinations required to determine brain death as well as the waiting periods between examinations” can result in prolonged waiting periods that can “have a negative effect on organ donation.”).

make death determination more complex.⁸⁷ Since the mid-twentieth century, advancements such as mechanical ventilation and defibrillation can restore heartbeat.⁸⁸ Where the patient has suffered catastrophic brain injury however, such interventions can lead to “a dead brain in a body whose heart is still beating . . . one of the more macabre products of modern technology.”⁸⁹ At the same time, modern innovations in the organ transplantation field have led to questions about whether and when it is ethically permissible to harvest organs from individuals with brain injuries whose heart and lung function are being artificially maintained.⁹⁰ Such developments have “altered the relationship between organ failure and death,” and changed the way dying occurs, raising concerns about when organ donation may begin.⁹¹

Whether a person is legally dead based on neurologic criteria (that is, brain dead) “presents a mixed legal and medical question.”⁹² In practice, although “it is for the law . . . to define the standard of death . . . it is for the medical profession to determine the applicable criteria, in accordance with accepted medical standards, for deciding whether brain death is present.”⁹³ Yet disagreement persists in the medical community as to precisely what constitutes brain death or when a declaration of brain death can or should be made. A “broad level of misunderstanding and confusion over brain death” exists, even among medical professionals, and remains “stubbornly immune” to efforts at professional education.⁹⁴

This is exacerbated by the fact that different criteria exist for determining what constitutes brain death. Such variances in diagnostic criteria allow for brain death to be determined in inconsistent fashions, using different testing protocols. For example, the Harvard Criteria for determining brain death require, *inter alia*, that the patient have a flat

87 James L. Bernat, *Brain Death and the Definition of Death*, in *NEUROETHICS: ANTICIPATING THE FUTURE* 336–37 (Judy Illes ed. 2017).

88 *Id.* at 337.

89 Christopher Pallis, *ABC of Brain Stem Death. Reappraising Death.*, 285 *BRITISH MED. J.* 1409, 1409 (1982); Katina Zheng et al., *Healthcare Professionals’ Understandings of the Definition and Determination of Death: A Scoping Review*, 8 *TRANSPLANTATION DIRECT*, 2022, at 4.

90 Michael A. De Georgia, *History of Brain Death as Death: 1968 to the Present*, 29 *J. CRITICAL CARE* 673, 673 (2014).

91 *Id.*; Zheng et al., *supra* note 90, at 1.

92 *In re Guardianship of Hailu*, 361 P.3d 524, 528 (Nev. 2015); *In re Welfare of Bowman*, 617 P.2d 731, 734 (Wash. 1980) (“The law has adopted standards of death but has turned to physicians for the criteria by which a particular standard is met.”).

93 *Bowman*, 617 P.2d at 731.

94 Bernat, *supra* note 88, at 342.

electroencephalogram (“EEG”).⁹⁵ However, the American Academy of Neurology (“AAN”) Criteria or the Minnesota Criteria may not require an EEG test at all for brain death to be declared.⁹⁶ As another example, while the Harvard Criteria require that brain death tests are repeated “at least 24 hours later with no change in finding,” the Minnesota Criteria and AAN Criteria may permit a waiting period of only twelve hours or even six hours later with no change in finding, after which point brain death can be declared.⁹⁷ Even among institutions that purport to utilize the AAN criteria, research indicates that “hospital policies for determining [brain death] . . . vary widely and often deviate from AAN guidelines in multiple domains of the process.”⁹⁸ Physicians making brain death determinations are granted discretion to exercise “considerable judgment when applying the criteria in specific circumstances.”⁹⁹ This discretion has led to “inconsistent diagnoses and conflicting results” amongst physicians diagnosing brain death, with a study of brain death determination of organ donors at various medical centers revealing “wide variability in approaches to [brain death] determination.”¹⁰⁰

Given the forgoing, brain death “continues to be questioned by some as being unscientific, or illogical, and contrived to facilitate organ donation.”¹⁰¹ Indeed, brain dead individuals whose hearts and circulatory-respiratory systems are still functioning have organs that are certainly suitable for donation.¹⁰² Per the President’s Commission for the

95 See, e.g., ROBERT M. VEATCH & LAINIE FRIEDMAN ROSS, *TRANSPLANTATION ETHICS* 55–58 (2d ed. 2015) (describing The Harvard Criteria-1968 for determining brain death, as compared to the Minnesota Criteria (1971), the National Institute of Neurological Diseases and Stroke (1977), Minnesota Medical Association Criteria (1978), Medical Consultants to the President’s Commission (1981), American Academy of Pediatrics (1987), American Academy of Neurology (1995), UK Academy of Medical Royal Colleges (2008), American Academy of Neurology (2010), American Academy of Pediatrics, Society of Critical Care Medicine and Child Neurology Society (2010)); see also David M. Greer et al., *Determination of Brain Death/Death by Neurologic Criteria: The World Brain Death Project*, 324 *JAMA* 1078, 1079 (2020); De Georgia, *supra* note 91, at 675; Bowman, 617 P.2d at 737; Harvard Medical School, Ad Hoc Committee, *A Definition of Irreversible Coma*, 205 *JAMA* 337, 337–40 (1968).

96 VEATCH & ROSS, *supra* note 96, at 55–58.

97 *Id.*

98 Claire N. Shappell et al., *Practice Variability in Brain Death Determination: A Call to Action*, 81 *NEUROLOGY* 2009, 2009 (2013).

99 G. Kevin Donovan et al., *Proposal for Revising the Uniform Determination of Death Act*, (Feb. 18, 2022), <https://www.thehastingscenter.org/defining-brain-death/>.

100 *Id.*; see also Shappell et al., *supra* note 99, at 2009.

101 Zheng et al., *supra* note 90, at 4.

102 Bernat, *supra* note 88, at 342–43 (Given that brain dead individuals are suited for

Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, “[t]he suitability of organs for transplantation diminishes rapidly once the donor’s respiration and circulation stop. The most desirable organ donors are otherwise healthy individuals who have died following traumatic head injuries and whose breathing and blood flow are being artificially maintained.”¹⁰³ By contrast, circulatory death, resulting from loss of blood circulation, yields organs “less desirable for transplantation.”¹⁰⁴

If medical professionals struggle to uniformly define and diagnose brain death, “misunderstanding of brain death by laymen is even more widespread.”¹⁰⁵ This uncertainty about brain death and resulting fear of incorrect death determination and premature organ harvesting has a chilling effect on potential donors.¹⁰⁶ Anecdotal accounts of individuals presumed dead but later regaining consciousness, or of organs prematurely harvested from the living, take on an added specter of truth when the legal and medical community itself is unclear about when and how to declare an individual dead.¹⁰⁷ Fears of those mistakes are heightened given research indicating that “[i]n spite of claims of near-perfect specificity in the diagnosis of brain death . . . the reality is that false positive misdiagnoses of brain death do occur.”¹⁰⁸

transplantation, some have argued that the entire concept of brain death was promulgated solely for the purpose of increasing organ availability. Such critics assert that “brain death represents a ‘legal fiction’ to permit organ donation,” and that “brain dead patients are not really dead but society creates the legal fiction of brain death to allow them to be declared dead for the societal benefits of organ donation.”).

103 PRESIDENT’S COMM’N FOR THE STUDY OF ETHICAL PROBS. IN MED. & BIOMEDICAL & BEHAVIORAL RSCH., *DEFINING DEATH: MEDICAL, LEGAL, AND ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH* 23 (1981).

104 Alexandra K. Glazier & Alexander M. Capfon, *NPR and US Legal Standards for Determining Death Are Not Aligned*, 22 AM. J. TRANSPLANTATION 1289, 1289 (2022).

105 Bernat, *supra* note 88, at 342; *see also* Daniela J. Lamas, *What Happens When the Brain Goes Quiet but the Heart Continues Beating?*, N.Y. TIMES, (Sept. 15, 2022), <https://www.nytimes.com/2022/09/15/opinion/death-brain-organ-donation.html>.

106 *See* Richard S. Kurz et al., *Factors Influencing Organ Donation Decisions by African Americans: A Review of the Literature*, 64 MED. CARE RSCH. & REV. 475, 512 (2007).

107 *See, e.g.*, Sydney Lupkin, *Patient Wakes Up as Doctors Get Ready to Remove Organs*, ABC NEWS, (July 8, 2013), <https://abcnews.go.com/Health/patient-wakes-doctors-remove-organs/story?id=19609438>.

108 Michael Nair-Collins & Ari R. Joffe, *Frequent Preservation of Neurologic Function in Brain Death and Brainstem Death Entails False-Positive Misdiagnosis and Cerebral Perfusion*, 14 AJOB NEUROSCIENCE 255, 255 (2023); Given the uncertainty surrounding brain death determination and organ donation, some clinicians have urged that “those who believe in the sanctity of life, regardless of whether they support or oppose the theoretical validity of brain-death criteria [must] oppose

I. Brain Death Determination in Underrepresented Communities

Concerns about brain death may be particularly acute among vulnerable and minority communities where historical distrust of the medical profession is only heightened when life-and-death determinations lack a clear scientific or medical-legal foundation.¹⁰⁹ Historical accounts of the medical profession and donees profiting from Black donors reinforce distrust of the healthcare system.¹¹⁰ The fact that Black people are diagnosed as brain dead at the highest rates per capita when compared to other ethnicities only augments such concerns.¹¹¹ Where life-and-death determinations appear to be based on the subjective judgments of physicians, suspicion of the organ donation

the use of brain-death criteria to obtain organs for transplantation in clinical practice.” Joseph M. Eble, *Brain Death: What Catholics Need to Know*, NAT’L CATH. REG., (Oct. 25, 2021), <https://www.ncregister.com/commentaries/brain-death-and-organ-donation>.

109 Kananeh et al., *supra* note 87, at 1.

A[fri]cans] A[mericans] less commonly consent to organ donation after B[rain] D[eath]. A[fri]cans] A[mericans] are more likely to believe in the importance of being buried intact, less likely than Caucasian families to know the wishes of their loved ones and to have a living will or discussion with their families. Lack of trust between the A[fri]cans] A[merican] community and the medical community may be another reason for low consent. Medical mistreatment and non-voluntary experimentation on slaves during the antebellum period and the Tuskegee Syphilis Study have been reported in the literature as possible explanations. In addition, A[fri]cans] A[mericans] more than Caucasians believe less will be done to save their lives if doctors know they are organ donors. Many report their interactions with healthcare providers as inadequate, which leads to lower consent rates.

Id.

110 See Chip Jones, *How a Historic Heart Transplant Exposed a Troubling Truth About Race and Health in America*, TIME, (Aug. 18, 2020), <https://time.com/5880419/heart-transplant-segregation/> (describing the circumstances surrounding the retrieval of organs from Bruce Tucker, a Black man whose organs were harvested before Tucker’s family was aware or informed of his death—in a segregated community with rumors of nighttime abductions and grave robbery for medical experimentation—and whose heart was transplanted into the body of “an ailing white businessman,” launching the storied careers of pioneering U.S. heart transplant surgeons).

111 Ali Seifi et al., *Incidence of Brain Death in the United States*, 195 CLINICAL NEUROLOGY & NEUROSURGERY, May 2020, at 2, 4 (“the highest rate of [brain death] per capita was within [B]lacks and Hispanics” and “Blacks increased incidence of BD versus whites was statistically significant; white residents’ rate of brain death was 40.6 percent that of [B]lacks”).

process is unsurprising. Among historically oppressed populations already suffering from racial inequities in the provision medical care, hesitation to donate is a logical result.¹¹²

Such misgivings are intensified by the highly emotional circumstances that can precede a brain death diagnosis. “The death of most people who become deceased organ donors is sudden, unexpected, and frequently tragic,” and can be difficult for families to come to terms with.¹¹³ In brain death cases, the donor’s family is “almost never prepared” and may not be willing to accept a declaration that their loved one has died, especially given that a brain dead individual may display physical signs that appear to indicate life such as a beating heart and warm skin.¹¹⁴ *Given the fact that* minority patients with traumatic brain injury experience “double the risk of in-hospital mortality than White/non-Hispanic patients,” opposition to brain death determinations are to be expected.¹¹⁵

The circumstances surrounding the death of Jahi McMath well illustrate the conditions in which such opposition to brain death determinations might unfold. In December 2013, Jahi McMath, a 13-year-old child, was admitted to Oakland Children’s Hospital for a routine surgery, and subsequently suffered post-surgery complications.¹¹⁶ Upon observing that she appeared to be in distress, Jahi’s family members sought assistance from hospital personnel.¹¹⁷ As Jahi’s condition worsened, her mother reported feeling “in [her] heart” that “if Jahi was a little white girl . . . we would have gotten a little more help and

112 Lillie D. Williamson et al., *A Qualitative Examination of African Americans’ Organ Donation-Related Medical Mistrust Beliefs*, 30 HOWARD J. COMM’NS. 430, 434–435 (2019).

Four types of medical mistrust were present in African Americans’ sentiments related to medical mistrust: societal distrust, distrust of institutions, distrust of medical institutions, and organ donation specific mistrust. These beliefs extend beyond physician mistrust to encompass historical and current race relations. The medical mistrust beliefs described by participants represented a continuum of more general societal mistrust to organ-donation specific medical mistrust.

Id.

113 Hanto, *supra* note 68, at 585.

114 *Id.*

115 Emma A. Richie et al., *Racial and Ethnic Inequities in Mortality During Hospitalization for Traumatic Brain Injury: A Call to Action*, 8 FRONTIERS SURGERY, June 2021, at 1, 10.

116 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>.

117 *Id.*

attention.”¹¹⁸ Jahi subsequently suffered cardiac arrest, and three days after her admission, she was declared brain dead.¹¹⁹ In the days following the brain death declaration, an organ procurement representative approached Jahi’s mother to ask for permission to harvest Jahi’s organs. Observing her daughter at the bedside, Jahi’s mother—expressing incredulity that her child was dead given that “her skin was still warm and soft and she occasionally moved her arms, ankles, and hips”—rejected the organ donation request.¹²⁰

The brain death diagnoses of Jahi McMath, and the subsequent objections of the family illustrate the type of uncertainty that can surround a determination of brain death and its effect on organ donation. *As McMath* demonstrates, a brain-dead individual sustained by a ventilator appears warm and breathing, making the determination of death exceedingly difficult for the family to grasp. *The brain dead* patient may still have a “heartbeat, a measurable blood pressure, produce[] urine, and ha[ve] good skin color and other indications that suggest life.”¹²¹ Reconciling the brain death determination with such visual signs of life is difficult. Ensuing requests to harvest organs may thus naturally be met with suspicion and hostility by the family if the organ donation request is seen as an effort to prematurely end the patient’s life. The death of Jahi McMath illustrates the heightened concerns of minority populations in the care of “a medical system that systemically ignores the vulnerable—particularly Black Americans.”¹²²

118 *Id.*; see also Michele Goodwin, *Revisiting Death: Implicit Bias and the Case of Jahi McMath*, 48 HASTINGS CTR. REP. S77, S78 (2018) (“On any given day in the United States, disparities in the quality of health care and health outcomes for people of color in comparison to whites are evidenced in American hospitals and clinics. As decades of research show, these disparities are not entirely explained by differences in patient education, insurance status, employment, income, expressed preference for treatments, and severity of disease. Instead, compelling research indicates that, even for African Americans able to gain access to health care services and navigate institutional nuances, disparities persist across a broad range of services, including diagnostic screening and general medical care, mental health diagnosis and treatment, pain management, HIV-related care, and treatments for cancer, heart disease, diabetes, and kidney disease.”).

119 *McMath v. California*, No. 15-cv-06042, 2016 WL 7188019, at *1 (N.D. Cal. Dec. 12, 2016); *Winkfield v. Children’s Hosp. Oakland*, No. 4:13-cv-05993, 2014 U.S. Dist. LEXIS 8560, at *1 (N.D. Cal. Jan 23, 2014); Aviv, *supra* note 117.

120 Aviv, *supra* note 117; *McMath*, 2016 WL 7188019, at *1; *Winkfield*, 2014 U.S. Dist. LEXIS 8560, at *1.

121 Hanto, *supra* note 68, at 585.

122 Goodwin, *supra* note 119, at S77.

2. Brain Death and Organ Donation: Client Considerations

The lack of medical-legal clarity or consistency in the definition of brain death and resulting public misunderstanding, mistrust, and litigation directly impact organ availability. Brain death and organ donation are inseparably interconnected. Organs from brain-dead people are particularly suitable for donation.¹²³ “The majority of organs transplanted are recovered from [brain-dead] patients,” and how brain death is determined necessarily affects the availability of organs for transplant.¹²⁴

Concerns about erroneous brain death determination, such as those raised by the McMath family and the media publicity surrounding brain death cases, create heightened public wariness about ceding control of one’s body to the medical system as an organ donor. Relinquishing control of one’s body to the medical system to make decisions as to when body parts may be removed is a decision the public is often uncomfortable with.¹²⁵ Individuals making organ donation decisions as part of their estate plan often express uncertainty and fear that if they agree to donate, medical professionals will stop lifesaving care, prematurely declare them dead, or improperly remove and distribute their organs.¹²⁶

123 See Abdul Mannan et al., *Heart Transplantation After the Circulatory Death: The Ethical Dilemma*, 6 J. FAM. MED. PRIMARY CARE 885, 885 (2017) (explaining that donors after brain death have been the major source of organ donation due to good perfusion of the organs).

124 Kananeh et al., *supra* note 87, at 1; see also David M. Greer et al., *Variability of Brain Death Policies in the United States*, 73 J. AM. MED. ASS’N NEUROLOGY 213, 213 (2016) (noting that “significant variability in the number of examinations required to determine brain death as well as the waiting periods between examinations” can result in prolonged waiting periods that “can have a negative effect on organ donation.”).

125 See, e.g., Ezra Gabbay & Joseph J. Fins, *Go in Peace: Brain Death, Reasonable Accommodation and Jewish Mourning Rituals*, 58 J. RELIGION & HEALTH 1672, 1672 (2019); Jessica McFarlin et al., *Ascertaining Death. Defining Brain Death and Exploring Religious Exceptions to the Diagnosis (FR213)*, 63 J. PAIN & SYMPTOM MGMT. 806, 806 (2022) (“Abrahamic faith traditions (Judaism, Christianity, and Islam) hold varying views on the acceptability of brain death as human death. Some religions reject the idea because of persistent scientific uncertainty. Others object to the definition because of incongruent theological or philosophical underpinnings. Several states and some countries have permitted religious accommodation in death determination if such a determination will ‘violate personnel religious beliefs of an individual.’”).

126 Melissa Moschella, *Brain Death and Organ Donation: A Crisis of Public Trust*, 24 CHRISTIAN BIOETHICS: I NON-ECUMENICAL STUD. MED. MORALITY 133, 138 (2018)

To help dispel those fears, advance healthcare directives that include appointment of a healthcare power of attorney and a living will may provide a tool that offers clients some degree of involvement or control over the decision as to when their organs will be harvested. State healthcare directive statutes affirm that every individual has the right to make their own healthcare decisions, as long as they are able to do so, or appoint a surrogate healthcare agent (a healthcare proxy) to do so on their behalf if they cannot make decisions for themselves.¹²⁷ And “[a]ll fifty states and the District of Columbia currently have statutory provisions recognizing advance directives in some manner, be they Living Wills, Health Care Proxies . . . or other instruments.”¹²⁸ Through living wills, individuals may additionally specify the treatment choices they would prefer at the end of life and grant their healthcare agent decision-making authority over end-of-life choices, including whether to withhold or withdraw life-prolonging medical interventions prior to death.¹²⁹ By articulating end-of-life and treatment wishes and appointing a healthcare agent through an advance directive, clients may find reassurance in having retained an element of oversight as to when and under what conditions donation will occur.

A carefully worded advance directive, together with a well-prepared healthcare agent to advocate for the client, may help to

(“Surveys about attitudes toward organ donation also indicate a lack of public trust in the medical profession regarding organ donation protocols in relation to the determination of death on neurological grounds. Fear of not receiving the same quality of care and fear of having one’s organs removed while still alive (because of skepticism regarding brain death) are prominent among the reasons why some people are hesitant to designate themselves organ donors, or to consent to organ donation on behalf of a loved one.”); *see also* Kurz et al., *supra* note 107, at 475; Laura Siminoff et al., *The Reasons Families Donate Organs for Transplantation: Implications for Policy and Practice*, 62 J. TRAUMA: INJURY, INFECTION, & CRITICAL CARE 969, 973 (2007).

127 *See, e.g.*, Illinois Health Care Surrogate Act, 755 ILL. COMP. STAT. ANN. 40/5 (West 1998).

128 Vanessa Cavallaro, *Advance Directive Accessibility: Unlocking the Toolbox Containing Our End-of-Life Decisions*, 31 TOURO L. REV. 555, 567 (2015).

129 *See, e.g.*, Alabama Natural Death Act, ALA. CODE § 22-8A-1 (2023); Illinois Health Care Surrogate Act, 755 ILL. COMP. STAT. ANN. 40/1 *et seq.* (West 1998); *see also* Unif. Health-Care Decisions Act § 1 *et seq.* (UNIF. L. COMM’N 1993); Brooke M. Benzio, *Advance Health Care Directives: Problems and Solutions for the Elder Law and Estate Planning Practitioner*, 26 ST. THOMAS L. REV. 37, 53 (2013) (“The documents utilized in the fifty states and the District of Columbia generally fall into one of three categories: ‘(1) living wills or advance health care directives; (2) durable powers of attorney for health care; and (3) a single document that encompasses both [(1) and (2)].’”).

ease fears of not receiving desired treatments before donation occurs. Attorneys should advise clients to document specific wishes and prepare a healthcare agent to advocate on their behalf to reassure the client that any and all treatments the client desires will be administered or withheld per the client's wishes. Such family or healthcare agent involvement should alleviate some of the fear surrounding organ donation. For example, within an advance directive, individuals might consider including directions that their body be treated in conformity with their personal or religious beliefs. "[M]any individuals with religious objections to the concept of brain death . . . want their beliefs respected," and may choose to so specify in their advance directives.¹³⁰ Such individuals might even choose in their advance directive to opt out of the definition of brain death altogether by including in the advance directive language such as, "I do not accept brain death as death and my organs may only be harvested after circulatory death."¹³¹

Those uncomfortable with the variability that exists in the criteria for determining brain death may specify the criteria to be used by saying: "If I am declared brain dead, my organs may be donated only if the Harvard Criteria for brain death are met."¹³² Although, "[t]he choice of criteria for measuring the death of the brain may seem like a technical matter of medical science to be left up to neurological scientists and professional associations," as previously explained, "there are significant differences across the criteria sets, and choosing among them inevitably raises moral and conceptual issues."¹³³ The medical, legal, and bioethical communities lack clear consensus as to when or how brain death should be determined, and the question of who should make determinations is a matter that has been subjected to the litigation process to resolve. Until consensus is reached, given the moral issues raised by the difference in brain death criteria, individuals have the

130 Pope, *supra* note 19, at S48 ("Over the past several years, families have filed lawsuits in California, Massachusetts, Michigan, Ontario, and Washington, D.C., . . . [and although] the courts have uniformly denied these claims, still more of these disputes are pending adjudication.").

131 See N.J. STAT. ANN. § 26:6A-5 (WEST 1991) (permitting conscientious objections to determination of death by neurological criteria).

132 D. Alan Shewmon, *Statement in Support of Revising the Uniform Determination of Death Act and in Opposition to a Proposed Revision*, J. MED. & PHIL.: FORUM BIOETHICS & PHIL. MED., 2021, at 1, 3 ("Those who do not accept the neurologic criterion, and desire to have their own death declared on the basis of the traditional circulatory-respiratory criterion, have the right not to have a concept of death imposed upon them contrary to their judgment and conscience.").

133 Robert M. Veatch, *Controversies in Defining Death: A Case for Choice*, 40 THEORETICAL MED. & BIOETHICS 381, 383 (2019).

option of utilizing advance directives or surrogate decision-makers to advocate for their own beliefs.

Of course, the question of whether patients should be permitted to choose or refuse death determinations for themselves raises philosophical, ethical, financial, legal, medical, social, and public policy concerns far beyond the scope of this article.¹³⁴ Moreover, client/patient decision-making autonomy about when death should be declared must be subject to some limitations in order to avoid forcing hospitals to treat cadavers and also conversely to avoid unlawful physician-assisted suicide.¹³⁵ Nevertheless, given the continuing variability about which protocols to use to determine brain death, permitting individuals to have a voice in the decisions about their own death—through advance directives and empowered surrogate decision-makers—could serve to reassure donors and their families as well as comfort and encourage those who wish to donate with the knowledge that their wishes will be respected.

Weaponizing advance directives as a tool to control death determinations and organ donation practices, however, may dangerously obstruct and interfere with clinical practice and the provision of medical care. “Although advance directives are intended to clarify a patient’s end-of-life wishes, physicians frequently find themselves struggling to reconcile bedside requests for care with those outlined in the documents with which they are presented.”¹³⁶ In such instances an advance directive document written by a legal professional may prove ineffective or confusing at best and obstructive at worst.¹³⁷ In addition, advance directives often do not make it into the medical record and may not be found until it is too late, and in cases where emergency medical care must be swiftly provided, such directives may be altogether overlooked.¹³⁸

Advance directives as a tool to manage end-of-life decisions

134 For a comprehensive analysis of such considerations *see id.*; Osamu Muramoto, *Is Informed Consent Required for the Diagnosis of Brain Death Regardless of Consent for Organ Donation?*, 47 J. MED. & ETHICS, 2021, at 1.

135 L. Syd M. Johnson, *The Case for Reasonable Accommodation of Conscientious Objections to Declarations of Brain Death*, 13 J. BIOETHICAL INQUIRY 105, 110–11 (2016).

136 Eileen F. Baker & Catherine A. Marco, *Advance Directives in the Emergency Department*, J. AM. COLL. EMERGENCY PHYSICIANS OPEN 270, 270 (2020).

137 *Id.* at 271 (“Living wills provide good guidance for the treatment of those in a persistent vegetative state, for those with debilitating disease, or for those who clearly wish to have comfort care only. They are more nebulous, however, with regard to acute care situations, especially those encountered in the [emergency department].”).

138 *See* Zhang & Cagle, *supra* note 44, at 1108–12.

have various additional shortcomings. Only a minority of U.S. residents have completed an advance directive, limiting their effectiveness, although the COVID-19 pandemic may have caused an increase in the completion of such documents.¹³⁹ In addition, “[a]dvance directive completion [is] associated with older age, more education, and higher income,” and is “less frequent among non-white respondents.”¹⁴⁰ Low health literacy negatively affects advance directive completion, and “people of all ages, races, incomes, and education levels, [as well as] people with limited reading skills or people for whom English is a second language—are affected by limited health literacy.”¹⁴¹ Although low health literacy impacts people of all backgrounds, there are some demographic groups whom it affects to a greater degree. “Low health literacy affects certain population subgroups disproportionately: people of lower socioeconomic status, racial and ethnic minorities, people with disabilities, those with psychiatric and other cognitive disorders, and the elderly.”¹⁴² Excluding those populations from the benefit of articulating treatment and end-of-life preferences for themselves and their families, leaving only those with sufficient resources the privilege of having such decisions prepared and recorded in advance, perpetuates inequity.

Moreover, utilizing advance directives to restrict medical discretion, and control when organ donation can occur could be viewed as sanctioning distrust of the organ donation system and reinforcing doubt about the legitimacy of medical practice. Mistrust of “doctors, hospitals, and the organ allocation system” are already “[t]he most common reasons cited for not wanting to donate organs,” so the use of advance directives as a tool to object to or reject death determinations risks pitting legal and medical professionals against each other.¹⁴³

Yet families and surrogate decision-makers are already finding alternative methods to advocate for themselves, through litigation and otherwise, in objection to medical determinations of brain death. Those without resources to prepare decisions in advance continue to find avenues for redress amidst the lack of legal and medical consensus

139 Catherine L. Auriemma et al., *Completion of Advance Directives and Documented Care Preferences During the Coronavirus Disease 2019 (COVID-19) Pandemic*, 3 JAMA NETWORK OPEN, July 2020, at 1–2.

140 Jaya K. Rao et al., *Completion of Advance Directives Among U.S. Consumers*, 46 AM. J. PREVENTIVE MED. 65, 65 (2014).

141 INSTITUTE OF MEDICINE OF THE NATIONAL ACADEMIES, *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* 157 (2015).

142 *Id.*

143 Susan E. Morgan et al., *In Their Own Words: The Reasons Why People Will (Not) Sign an Organ Donor Card*, 23 HEALTH COMMUN 23, 23 (2008).

surrounding death determinations and organ donation. For example, families can refuse to permit doctors to conduct required diagnostic testing to determine whether the patient is brain dead, where consent of the family is required for such testing.¹⁴⁴ Such strategies effectively allow families to decide for themselves when death should be declared.¹⁴⁵

Absent statutory or institutional change, such challenges to the end-of-life and organ donation process may continue to be raised through informal or formal hospital dispute resolution processes.¹⁴⁶

144 As an illustration, families have recently become embroiled in litigation after refusing physicians permission to conduct an apnea test on the patient whom the physicians believed to be brain dead. Such apnea tests are used as a tool to determine brain death. See Thaddeus Mason Pope, *Brain Death Forsaken: Growing Conflict and New Legal Challenges*, 37 J. LEGAL MED. 265, 269, 311–12 (2017) (discussing litigation involving the question of consent for apnea testing, and noting that “[b]y object[ing] to the apnea test,” such “families have been able to prevent clinicians from determining brain death.”); Sarang Biel & Julia Durrant, *Controversies in Brain Death Declaration: Legal and Ethical Implications in the ICU*, 22 CURRENT TREATMENT OPTIONS NEUROLOGY, Mar. 2020, at 1, 8 (describing the case of 6-year-old Allen Calloway (Montana) whose mother refused brain death testing after the drowning of her son, and Miranda Lawson (Virginia) whose parents refused apnea testing to determine her death, and sought a temporary restraining order); Pope, *supra* note 19, at S47–48; see generally Ivor Berkowitz & Jeremy R. Garrett, *Legal and Ethical Considerations for Requiring Consent for Apnea Testing in Brain Death Determination*, 20 AM. J. BIOETHICS 4 (2020).

145 See generally Kristin Walter, *Brain Death*, 324 JAMA III6 (2020) (An apnea test—i.e. “temporarily removing a patient from mechanical ventilation and observing for spontaneous breaths”—is one of the conditions that must be present for a diagnosis of brain death).

146 ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING* § 3.25 (3d ed. 2004 & Supp. 2017) (“The primary alternative to judicial review of decisions about life-sustaining treatment is some form of review in the clinical setting. As a practical matter, there are likely to be one or more formal or informal reviews within health care institutions, by persons including the attending physician, consultant physicians, health care administrators, legal counsel, and/or a committee”); Thaddeus Mason Pope, *Multi-Institutional Healthcare Ethics Committees: The Procedurally Fair Internal Dispute Resolution Mechanism*, 31 CAMPBELL L. REV. 257, 272–73 (2009).

Judicial review is generally thought to be an inappropriate mechanism for resolving medical treatment disputes. First, it is cumbersome, being both time-consuming and expensive. Thus, it cannot usefully address complex, urgent medical issues. Second, as courts are adversarial and open to the public, they are an unwelcome forum in which to resolve sensitive medical treatment disputes. Third, judicial review is an encroachment on the medical profession. In contrast, the responses of ethics committees are ‘more rapid and sensitive’ and ‘closer to the treatment setting.’ ‘[T]heir deliberations are informal and typically private,’ which is important for medical decisions and

Finally, litigation continues to offer a viable avenue for families to continue to assert their objections, as has already occurred with some success in *McMath*.¹⁴⁷ Given the uncertainty surrounding brain death declarations, the reality is that “more families have been emboldened to translate their concerns into legal claims challenging traditional brain death rules.”¹⁴⁸ The use of advance directives as a preventive tool could serve to avoid such litigation altogether by allowing patients and families to articulate their decisions in advance in an effort to regain some autonomy and control over the brain death decision, which directly impacts organ donation availability.

3. Brain Death and Organ Donation: Efforts to Revise the UDDA

In an effort to address the concerns surrounding brain death and organ donation the Uniform Law Commission has initiated efforts to create a new, clearer definition of death. In 2021, the Uniform Law Commission established a Determination of Death Committee to update and revise the UDDA.¹⁴⁹ The drafting committee has undertaken the process with a “focus on enhanced transparency and accountability” and an objective of “avoid[ing] conflict and litigation.”¹⁵⁰

Efforts by the Uniform Law Commission to revise the UDDA seek to create a definition of death that can be applied uniformly across all fifty states. The revision plan has struggled to contend, however,

for the informal resolution of disputes.

Id. at 272–73.

147 See Lola Butcher, *Commission Will Revise the Uniform Determination of Death Act What That Means for Defining Brain Death*, *NEUROLOGY TODAY* (Oct. 21, 2021), https://journals.lww.com/neurotodayonline/fulltext/2021/10210/commission_will_revise_the_uniform_determination.10.aspx (“Only about five to 10 lawsuits are filed each year. ‘But there are probably 10 times as many cases, or more, in hospitals where you have family saying, ‘I object,’ to the brain death determination.”).

148 Pope, *supra* note 19, at S46, S48 (“Over the past several years, families have filed lawsuits in California, Massachusetts, Michigan, Ontario, and Washington, D.C., [and although] the courts have uniformly denied these claims, still more of these disputes are pending adjudication.”).

149 Memorandum from Samuel A. Thumma, Committee Chair, Eric Weeks, Committee Vice Chair, & Professor Nita A. Farahany, Committee Reporter, to Commissioners, Advisors and Observers Serving on the Uniform Law Commission’s Drafting Committee to Revise the Uniform Determination of Death Act (Sept. 23, 2021), <https://www.uniformlaws.org/committees/community-home/librarydocuments?communitykey=a1380d75-62bc-4a5b-ba3a-e74001a9ab57&LibraryFolderKey=&DefaultView=>.

150 *Id.*

with the problem that determining when death has occurred is much more than a matter of law or medicine, but implicates “some of the most basic questions of human existence: the relation of mind and body, the rights of religious and philosophical minorities, and the meaning of life itself.”¹⁵¹ Moreover, the Uniform Law Commission’s efforts to revise the determination of death have occurred in a particularly polarized and politically charged climate marked by intense disagreement about when life begins and ends.¹⁵² As of September 2023, the Uniform Law Commission indefinitely suspended its efforts to revise the UDDA.¹⁵³

Amongst the many viewpoints about what should constitute death and brain death, propositions for the new UDDA include broad criteria that allow for a greater subset of individuals to be declared dead than the current UDDA permits.¹⁵⁴ Such proposals that seek to declare brain death broadly are challenged, however, as so expansive that they risk dangerously encompassing a subset of individuals who may not be dead.¹⁵⁵ In contrast, alternative proposals seek to define brain death narrowly, limiting the conditions under which a person can be declared dead.¹⁵⁶ Narrow interpretations, however, risk keeping dead people on artificial supports, such as mechanical ventilation, which may create a strain on scarce medical resources. Offering a middle ground approach, alternative proposals seek to correct the diagnostic criteria for determining brain death to improve their accuracy while allowing

151 VEATCH & ROSS, *supra* note 96, at 126.

152 Truog & Magnus, *supra* note 21, at 2335–36.

153 *Id.* at 2336.

154 Proponents of the “neurorespiratory criteria” for determination of brain death, propose that for brain death to be declared, the individual must sustain a brain injury leading to permanent loss of (a) the capacity for consciousness, (b) the ability to breathe spontaneously, and (c) brainstem reflexes. UNIFORM LAW COMMISSION, DETERMINATION OF DEATH COMMITTEE: 2022 APRIL 21-22 COMMITTEE MEETING (April 21–22, 2022), <https://www.uniformlaws.org/viewdocument/2022-april-21-22-committee-meeting?CommunityKey=a1380d75-62bc-4a5b-ba3a-e74001a9ab57&tab=librarydocuments>; *see generally* Bernat, *supra* note 88.

155 Shewmon, *supra* note 133, at 9 (“the Guidelines that are being proposed as the statutorily mandated medical standard entail a non-negligible risk of misdiagnosing a live patient as dead (contrary to the claims of their drafters and proponents.”).

156 Stephen E. Doran & Joseph M. Vukov, *Organ Donation and Declaration of Death: Combined Neurologic and Cardiopulmonary Standards*, 86 LINACRE Q. 285, 292–93 (2019) (positing that “[p]atients who meet brain death criteria . . . are unambiguously in the process of dying and are unambiguously dead when the heart and lung cease functioning”, and suggesting combined neurological and cardiopulmonary criteria must be met before death can be declared.”).

individuals to opt out of a brain death diagnosis if they so desire.¹⁵⁷ Examples of opt-out provisions exist, for example, in New Jersey, which permits rejection of a brain death declaration on personal religious grounds.¹⁵⁸

Whatever definition is ultimately selected, a revised definition of death or brain death is unlikely to satisfy the varied personal, religious, and philosophical beliefs of a diverse public. Individuals and surrogates suspicious of the concept of brain death, or who reject the concept of brain death entirely, can and will continue to find means to assert their objections to brain death determinations, whether through informal dispute resolution, the litigation process as in *McMath*, or preparation of specific advance directives to opt out of brain death. The legal profession may thus find itself increasingly called upon in the death-determination arena to advocate for those who wish to assert their objections and prepare those who wish to clarify their end-of-life wishes in conformity with their individual philosophical or religious values, regardless of UDDA definitions to the contrary.

B. Circulatory-Respiratory Death and Organ Donation: Concerns and Controversies

In contrast to brain death, which is characterized by “irreversible cessation of all brain functions,” under the current UDDA, “circulatory death” is characterized by “irreversible absence of circulation.”¹⁵⁹ Organ donations that occur after circulatory death (“donations after

157 See generally Donovan et al., *supra* note 100.

158 N.J. STAT. ANN. § 26:6A-5 (West 1991). The statute provides:

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 . . .

Id.

159 ABHINAV HUMAR ET AL., *ATLAS OF ORGAN TRANSPLANTATION* 25 (Abhinav Humar & Mark L. Sturdevant eds., 2d ed. 2015); Donation after Circulatory Death is the “[r]ecovery of organs and or tissues from a donor whose heart has irreversibly stopped beating, previously referred to as non-heart-beating or asystolic donation.” *Glossary*, ORGAN PROCUREMENT & TRANSPLANTATION NETWORK, <https://optn.transplant.hrsa.gov/patients/glossary/> (last visited Jan. 9, 2024).

circulatory death” or “DCDs”), may be either planned donations or unplanned donations.

Unplanned donations after circulatory death, may occur, for example, after medical emergencies such as cardiac arrest, where attempts at resuscitation fail. After a determination that circulation has irreversibly stopped, and if the patient or surrogate authorized donation, the medical facility can procure organs from the decedent.¹⁶⁰

Planned donations after circulatory death occur after the patient or their surrogate refuses life support or withdraws from life support at the end of life. The process of planned donation after circulatory death “involves the withdrawal of life-sustaining treatment, followed by a declaration of death after permanent cessation of circulation.”¹⁶¹

After the heart stops and circulatory and respiratory functions cease, death is declared, and the medical facility can harvest organs from the decedent.¹⁶² For *planned* donations after circulatory death, the decision to withdraw or refuse life support can occur in real time or may have been made previously in a written advance healthcare directive.¹⁶³ “In practice, most donations after circulatory death are done in a controlled manner following elective withdrawal of life support.”¹⁶⁴

Heightened awareness of and interest in organ donation has resulted in a rise in *planned* donations after circulatory death, due to “a greater interest of families of dying patients in donating organs and from the spread of hospital [donation after circulatory death] programs” that have increased the frequency of DCD donation.¹⁶⁵ *Planned* DCD donations benefit the public by increasing the supply of available organs, helping to address the critical issue of organ unavailability.¹⁶⁶

160 VEATCH & ROSS, *supra* note 96, at 68.

161 Ryan D. Rosen et al., *Trauma Organ Procurement*, STATPEARLS, at 2 (Jul. 31, 2023), <http://www.ncbi.nlm.nih.gov/books/NBK555947/>.

162 VEATCH & ROSS, *supra* note 96, at 64–72; Erik K. St. Louis & Richard R. Sharp, *Ethical Aspects of Organ Donation After Circulatory Death*, 21 CONTINUUM: LIFELONG LEARNING IN NEUROLOGY 1445, 1445 (2015).

163 Louis & Sharp, *supra* note 163, at 1445.

164 *Id.*

165 James L. Bernat & Nathaniel M. Robbins, *How Should Physicians Manage Organ Donation After the Circulatory Determination of Death in Patients with Extremely Poor Neurological Prognosis?*, 20 AMA J. ETHICS 708, 709 (2018); Rosen et al., *supra* note 162, at 2 (In general, “to avoid any conflicts of interest, the decision to withdraw care must take place before any discussion of organ donation.” In addition, “members of the organ procurement/transplant teams should not be involved in the process of care withdrawal or the declaration of death.”).

166 Rosen et al., *supra* note 162, at 2.

1. Donation after Circulatory Death and Organ Donation: Client Considerations

a. Inconsistencies in How and When Death Is Declared After Circulatory Death

For both planned and unplanned DCD, ethical-legal concerns can arise in ascertaining when the patient is dead in order for the harvesting of organs to begin. Given the fact that organ harvesting commences immediately after pronouncement of death, a repeatedly expressed concern of potential donors is fear that death will be declared and organs harvested too soon if they agree to become donors.¹⁶⁷ Such concerns—that the medical team will prematurely harvest organs or prioritize organ procurement over and above saving the donor's life—dissuades individuals from agreeing to become donors.

These fears are exacerbated by the fact that determining when circulatory death has occurred (that is, when circulatory-respiratory function is “irreversibly lost”) is not always precise. For DCD donation, organ harvesting can only begin after circulatory and respiratory function are irreversibly lost.¹⁶⁸ However, determining when that “irreversible loss” occurs depends on which standards or protocols the hospital uses.¹⁶⁹ For example, variations exist between hospital protocols as to the length of time that must pass without a heartbeat before death is declared.¹⁷⁰ This means that in some hospitals, individuals can be declared dead sooner than other hospitals might permit.¹⁷¹ This

167 Lizza, *supra* note II, at 45.

168 Louis & Sharp, *supra* note 163, at 1445.

169 VEATCH & ROSS, *supra* note 96, at 69–70 (noting that different criteria sets chose different lengths of time for apnea testing. The Harvard criteria (1968), 3 minutes; University of Minnesota (1971), 4 minutes, National Institute of Neurological Disease and Stroke (1977), 15 minutes, Minnesota Medical Association (1978), 3 minutes, Presidents Commission (1981), 10 minutes, AAN (1995), 8 minutes; and AAN (2010) 8-10 minutes.”).

170 *Id.*

171 Maxine M. Harrington, *The Thin Flat Line: Redefining Who Is Legally Dead in Organ Donation After Cardiac Death*, 86 DENV. U. L. REV. 335, 363 (2009).

The lack of consistency among hospital protocols in the pronouncement of death is . . . troublesome. If Sue is withdrawn from life support in Pittsburgh, she is dead after two minutes without evidence of cardiac activity. If Sue is in Shreveport, Louisiana, she will not be declared irreversibly dead until five minutes transpire after asystole. In other words, in Shreveport, Sue is just mostly dead after two minutes and her organs cannot be recovered while, in

inconsistency “leaves patients or families who are considering donation in a disconcerting situation where they may not know or be able to choose which version of ‘death’ will be applied to them.”¹⁷²

Inconsistencies in when death is declared perpetuate fear that organs may be harvested before the donor is dead.¹⁷³ Some clients making organ donation decisions may not be concerned with this imprecision given that the difference in hospital protocols for determining death may constitute only a matter of minutes. Such clients may agree to organ harvesting, despite the uncertainty. Others, however, may be hesitant to donate in light of such inconsistencies, or may be susceptible to misinformation based on the lack of clarity.¹⁷⁴ What is clear, however, is that “variations in the timing of death do not engender confidence in the organ transplant system, which depends on the trust of potential donors and their families that a physician will not prematurely declare them dead to harvest organs.”¹⁷⁵

For legal professionals counseling clients with such organ donation fears and concerns, given the highly technical medical considerations involved, collaboration with and input from the medical profession is necessary. Legal practitioners providing such end-of-life planning services to their clients regularly encounter clients who articulate such fears as the reason for their refusal to donate.¹⁷⁶ Equipping

Pittsburgh, Sue is really dead and her organs can be taken.

Id.

172 *Id.*

173 Moschella, *supra* note 127, at 138 (“Surveys about attitudes toward organ donation also indicate a lack of public trust in the medical profession regarding organ donation protocols in relation to the determination of death on neurological grounds. Fear of not receiving the same quality of care and fear of having one’s organs removed while still alive (because of skepticism regarding brain death) are prominent among the reasons why some people are hesitant to designate themselves organ donors, or to consent to organ donation on behalf of a loved one.”); Kurz et al., *supra* note 107, at 507; Siminoff et al., *supra* note 127, at 969–78.

174 See Harrington, *supra* note 172, at 364 (examining whether the “academic discussion about the time of death in DCD” really matters, given that “prospective donors who are voluntarily withdrawn from life support in a hospital are not going to be resuscitated and their brain function will soon be irretrievably lost due to lack of cardiac function”).

175 *Id.* at 363.

176 See David M. English, *Gift of Life: The Lawyer’s Role in Organ and Tissue Donation*, PROB. & PROP., March/April 1994, at 10, 12 (“Many misconceptions about organ and tissue donation are a major reason for the failure of individuals and families to follow through with donations. Reluctant donors fear that: the physician will begin the donation procedure while the donor is still alive or will hasten the donor’s death to obtain needed organs; organ or tissue donation will result in the

legal professionals with the tools or resources to meaningfully address such concerns may be one method among many of improving public organ donation literacy by providing reliable, impartial information about the donation process that considers not only the best interests of potential organ recipients but the best interests of the donors as well.

b. Pre- and Post-Mortem Procedures to Maintain Organ Viability

Another related source of potential concern in the context of DCD arises when the family is not aware or does not understand that before and after death, the patient or decedent may need to receive supportive treatments or interventions to maintain organ viability.¹⁷⁷ Patients and families “rarely realize that their desire to be an organ donor and their desire to forego certain treatments at the end of life are often mutually exclusive” and that “[t]he need to preserve organ[s] . . . for donation often requires the very measures that will prolong life when death is desired.”¹⁷⁸ Patients and families who have decided to withdraw or withhold treatment may thus be surprised and troubled by pre- or post-mortem organ donation interventions, and may refuse such interventions, potentially interfering with organ viability and setting the stage for conflict or litigation with hospitals and organ procurers.¹⁷⁹

disfigurement of the donor’s body; the donor’s family or estate will have to pay for the procedure; donation may violate the tenets of the donor’s religion; and donation will delay the donor’s funeral arrangements.”).

177 Christopher P. Michetti, *Patient-Centered Practices in Organ Donation*, 20 AM. J. TRANSPLANTATION 1503, 1503, 1505 (2020); Richard J. Bonnie, et al., *Legal Authority to Preserve Organs in Cases of Uncontrolled Cardiac Death: Preserving Family Choice*, 36 J. LAW, MED. ETHICS 741, 743 (2008) (“[I]n the typical case of organ donation, when death has been declared according to neurological criteria, it is standard procedure for hospitals to maintain organ viability until confirmation of donation status is obtained. Many procedures already underway before the potential donor died, such as mechanical ventilation and use of invasive lines, are continued. In addition, the transplant team typically initiates *new procedures*, such as the following: collecting blood, urine, and sputum for analysis to determine candidacy for donation; beginning new medications in attempts to maintain the now-dead body’s physiologic ‘balance’ and, if they are not already in place, inserting invasive lines to measure pressure in heart, lungs, and other cardiopulmonary parameters, and to administer medications and fluids.”).

178 Michetti, *supra* note 178, at 1503; Kim J. Overby et al., *Addressing Consent Issues in Donation After Circulatory Determination of Death*, 15 AM. J. BIOETHICS 3, 3 (2015); Bernat & Robbins, *supra* note 166, at 713 (“There is evidence that surrogate consent for DCDD currently is inadequate because . . . surrogates lack an understanding of the process of dying and the impact of donation.”).

179 Bernat & Robbins, *supra* note 166, at 708 (observing that even within the medical

When a patient agrees to be a donor, it arguably follows that the patient agrees to the medical procedures required to sustain the organs for donation. Yet, where such procedures are intrusive, or where the family has already made a decision to withhold or withdraw all treatments, the family may refuse further procedures that may be needed to maintain organ viability. For example, where a patient on life-sustaining treatment has consented to planned DCD donation, if the family seeks to withdraw life-sustaining treatment to end the patient's life and suffering, organ procurers may nevertheless insist that the family wait until a determination of organ viability can be made, compelling families to delay the process of dying, which can create significant distress for the family, moral uncertainty for clinicians, and protraction of suffering for the patient until an organ viability determination can be made.¹⁸⁰

Adding further complexity, the donor themselves may have been unaware of and might not have consented to such pre- or post-mortem procedures had they been informed. Moreover, advancements in medical science may allow for retrieval of organs by methods or interventions the donor may not have anticipated—as in the case of normo-thermic reperfusion, which some argue permits organ retrieval in violation of the Dead Donor Rule.¹⁸¹ Uncertainty can thus arise about

community itself “whether and how donor consent should be seen as authorizing manipulation of a living donor during the dying process solely for to benefit of the organ recipient”).

- 180 Robert D. Truog, *Consent for Organ Donation – Balancing Conflicting Ethical Obligations*, 358 N. ENGL. J. MED. 1209, 1211 (2008) (“Although consent from the next of kin is required for any [pre]mortem procedures . . . families may feel pressured to give consent by OPO representatives who choose to assume that the patient's general willingness to be an organ donor indicates a willingness to undergo these additional procedures before death, which may not be the case.”); see also Jason N. Batten et al., *Changing the Focus in the Donation After Circulatory Death Debates*, 23 AM. J. BIOETH. 48, 48–49 (2023) (discussing challenges clinicians face when disagreement between OPO and family arises, and lack of guidance for addressing such moral dilemmas).
- 181 See *Ethics, Determination of Death, and Organ Transplantation in Normothermic Regional Perfusion (NRP) with Controlled Donation after Circulatory Determination of Death (cDCD): American College of Physicians Statement of Concern* (April 17, 2021), https://www.acponline.org/sites/default/files/documents/clinical_information/resources/end_of_life_care/ethics_determination_of_death_and_organ_transplantation_in_nrp_2021.pdf.

It is important to understand what NRP-cDCD entails. After determination of circulatory death, the donor's chest is opened (as would normally happen in organ procurement). Recognizing the potential for restoration of circulation to result in cerebral

whether the donor's organ gift encompassed consent to such medical interventions. This can lead to disagreement between medical providers, organ procurement organizations, and family, resulting in conflict that risks disrupting the death and dying process.

Increasing recognition of a need to “inform the public and to possibly incorporate consent” for certain interventions into the organ donation decision continues to be hindered by a lack of clarity as to how to do so.¹⁸² In an effort to address this issue, some state advance directive statutes include explanatory language to ensure that the donor is aware of and authorizes medical interventions needed to sustain the body for the donation to occur.¹⁸³ Some state statutes go even further, restricting family from interfering with organ viability once a donor authorizes donation.¹⁸⁴ Indeed, UAGA, in certain circumstances, limits

reperfusion . . . various techniques such as ligating arteries or placing intravascular balloons or shunts are used to prevent cerebral reperfusion and bring on brain death. Perfusion is deemed regional, primarily because circulation to the brain has been actively excluded. The donor is then quickly connected, via cannulation of large vessels, to an ECMO or bypass circuit that restores circulation and enables warm perfusion of the organs. This includes the heart, which may then resume beating. Thus, the determination of irreversibility—necessary for the certification of death of the patient made moments before—was apparently inaccurate since circulation is restored. And then, according to one protocol, “standard DBD procurement will commence” because the patient is now dead by brain death criteria—due to actions taken by the physicians procuring the organs.

Id. The controversy surrounding the new organ harvesting procedure referred to as Normothermic Regional Perfusion (“NRP”) illustrates the ethico-legal concerns surrounding removal of organs after circulatory death that can arise with advancements in medical science. See e.g., Matthew DeCamp et al., *POINT: Does Normothermic Regional Perfusion Violate the Ethical Principles Underlying Organ Procurement? Yes*, 162 CHEST 288 (2022) (arguing that NRP violates the dead donor rule); see also Matthew J. Weiss et al., *Ethical Considerations in the Use of Pre-Mortem Interventions to Support Deceased Organ Donation: A Scoping Review*, 35 TRANSPLANTATION REVS., June 2021, at 1; Brendan Parent, *Partially Revived Pig Organs Could Force a Rethink of Critical-Care Processes*, 608 NATURE 32, 32 (2022) (describing NRP); Glazier & Capron, *supra* note 105, at 1289.

182 Weiss et al., *supra* note 182, at 1.

183 See e.g., 20 PA. CONS. STAT. § 5471 (West 2019) (“If I have authorized donation of an organ (such as a heart, liver or lung) or a vascularized composite allograft . . . I authorize the use of artificial support, including a ventilator, for a limited period of time after I am declared dead to facilitate the donation.”).

184 The Kansas Uniform Anatomical Gift Act provides, for example, that “[i]f a prospective donor has a declaration or advance health-care directive, measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor, unless

surrogate interference once the patient agrees to donate, allowing for procedures required to ensure medical suitability of the organs, even if the healthcare directive contains contradictory instructions.¹⁸⁵ Though UAGA grants OPOs statutory authority to maintain viability of the organs of a consenting donor, healthcare decision-making acts grant what may be conflicting statutory authority to surrogate decision-makers to make healthcare decisions (including withdrawal of life-sustaining treatment). These competing sources of governing statutory authority can result in uncertainty for donors and their families. Absent clarity as to the patient's wishes, or consensus between the patient, family, hospital, and OPO, the conflict between the surrogate's authority to make health decisions and the OPO's goals of maintaining organ viability may result in legal action. Indeed, such conflict has resulted in at least one instance of litigation in which a family member alleged infliction of "emotional

the declaration expressly provides to the contrary." KAN. STAT. ANN. § 65-3240(b) (West 2007); N.J. STAT. ANN. § 26:6-89(d) (West 2008) (The New Jersey Anatomical Gift Act (providing that "[w]hen a hospital refers an individual who is dead or whose death is imminent to a procurement organization, and the organization has determined based upon a medical record review that the individual may be a prospective donor, then the organization may conduct any blood or tissue test or minimally invasive examination that is reasonably necessary to evaluate the medical suitability of a part."); N.Y. PUB. HEALTH LAW § 4306-a (McKinney 2023) (New York Anatomical Gifts Act provides that if the donor's advance health-care directive is "in conflict with the express or implied terms of a potential anatomical gift with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy, the prospective donor's attending physician and the prospective donor shall confer to resolve the conflict If such prospective donor is incapable of resolving the conflict, and the patient in such declaration, directive, or proxy document did not expressly reject being a donor, then the health care proxy . . . shall act for the patient to resolve the conflict Such conflict must be resolved expeditiously. . . . Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the patient if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.").

185 The Revised UAGA provides:

If a prospective donor has a declaration or advance health-care directive and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy ... [b]efore resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.

Revised Unif. Anatomical Gift Act § 21 (UNIF. L. COMM'N 2006).

pain and suffering” caused by the OPO or hospital requiring continued supportive interventions to maintain organ viability in contravention of the family member’s request to remove the potential donor from the supportive equipment.¹⁸⁶

To address any potential family conflict within an advance directive, clients who wish to do so could include caveats such as “my agent can authorize, withhold, or withdraw treatment, even if such decisions make my organs no longer viable for donation” or “my agent can authorize or refuse any treatments or procedures, including those required for organ donation to occur” and “I do not want my organs harvested until my healthcare agent approves.” Such language could provide the potential donor with the reassurance that a trusted third-party agent will be involved in the decision-making process as to when organs will be harvested and can reject or prevent donation if concerns arise. Yet, as previously discussed, advance directives are limited in their effectiveness, given that they are not universally used, and may not be available when needed.

Other proposals to better inform the public about the nuances of their organ donation choice include the use of more comprehensive questionnaires when members of the public are asked to become donors at driver’s license offices or through online organ donation registries.¹⁸⁷ Such questionnaires would allow for more in-depth discussion of the potential donor’s goals and wishes, including the nature and extent of pre- or post-mortem interventions they would be willing to endure.¹⁸⁸ The use of more comprehensive questionnaires of this variety would “give potential donors an opportunity to clearly express the importance of organ donation to them, and which burdens they are willing to

186 *Pleasure v. Louisiana Organ Procurement Agency*, 83 So. 3d 174, 176 (La. Ct. App. 5 Cir. 2011), *writ denied*, 85 So. 3d 1248 (La. Ct. App. 2012) (widow alleged “that she requested that all life support be terminated after her husband was declared brain dead, but that the hospital continued those treatments while it determined whether his organs were viable for donation” and “that these continued treatments caused her unnecessary mental and emotional pain and suffering”), *dismissed on other grounds*. Resolution of such prospective litigation may depend on specific state law and factors such as the patient’s known or implied wishes, whether the patient is alive and being kept on life support in anticipation of donation (pre-mortem support), or whether the patient is legally dead (i.e. brain dead), and being kept on supportive treatments solely to maintain organ viability (post-mortem support), with the authority of the healthcare agent resting, in part, on whether the patient is alive or dead.

187 *See generally* Moorlock & Draper, *supra* note 37.

188 *Id.* at 8.

shoulder to become an organ donor.”¹⁸⁹

There is clearly expressed concern among scholars that current organ donation processes do not adequately provide the donor with enough information to make a knowledgeable decision or provide informed consent for the various procedures undertaken to maintain organ viability.¹⁹⁰ Nor can any one profession alone fill the information gap. As a result, the likelihood of families and surrogates continuing to find themselves unprepared and distressed by the organ donation process persists, amplifying distrust in the organ procurement process and leading to objections to donation through the wielding of the family veto.

IV. FAMILY DISAGREEMENT: THE FAMILY VETO

In general, once an individual authorizes donation of their organs, that decision must be honored. First-person consent precludes third parties from overriding the decision to donate. UAGA makes clear that “in the absence of an express, contrary indication by the donor, a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor’s body or part if the donor made an anatomical gift of the donor’s body or part.”¹⁹¹

Nevertheless, for a variety of reasons, families continue object to donations even after the decedent has expressly authorized the gift of their organs. Although the factual circumstances surrounding family refusals are unique in every case, the circumstances surrounding the death of Hollywood screenwriter Heidi Ferrer provide one illustration of how such a dispute may unfold.

In May 2021, Hollywood screenwriter Heidi Ferrer died by suicide following a year-long battle with long-haul COVID-19.¹⁹² Some time prior to her death, Heidi had registered as an organ donor.¹⁹³ However, upon her death, her husband objected to donation of her organs for transplant out of concern that her organs, if compromised or infected

189 *See id.*

190 Weiss et al., *supra* note 182, at 6; Moorlock & Draper, *supra* note 37, at 1 (arguing that “in order to be confident that a patient would really wish to go ahead with the various interventions and procedures that now accompany organ donation, more nuanced information than a simple ‘yes’ or ‘no’ may be required”).

191 Revised Unif. Anatomical Gift Act § 8(a) (UNIF. L. COMM’N 2006).

192 Roni Caryn Rabin, *She Died With Long Covid. Should Her Organs Have Been Donated?*, N.Y. TIMES (Nov. 7, 2021), <https://www.nytimes.com/2021/11/07/health/covid-organ-transplants.html>.

193 *Id.*

by COVID-19, would be harmful to the organ recipient.¹⁹⁴ Instead, her husband requested instead that her organs to be used for scientific research only, and not for transplant.¹⁹⁵ The hospital refused his request on grounds that he had no authority to make such a demand—Heidi herself had included no such limitations on the use of her organs.¹⁹⁶ Over her husband’s objections that his wife “would not have wanted this,” the hospital harvested several organs from Heidi’s body and donated her kidneys.¹⁹⁷

As evidenced by the donation of Heidi Ferrer’s organs over her husband’s objections and personal interpretations of her wishes, state statutes, in conformity with UAGA, provide that in general, first-person authorization of organ donation is to be upheld even in the face of family objections. “[F]irst person authorization (“FPA”) is based on the principle that a decision [to donate] by a person with decision-making capacity should be respected even after he or she dies.”¹⁹⁸ Although first-person authorization to donate is to be respected, families nevertheless repeatedly raise objections and seek to veto or overturn the donation decision for myriad reasons.

The death of Elijah Smith provides another such example. In 2013, twenty-one-year-old Elijah Smith suffered a brain injury after being struck by a vehicle.¹⁹⁹ Following a determination of brain death, the OPO argued that, per the designation on his driver’s license, Elijah had consented to donate his organs.²⁰⁰ On learning of the OPO’s intent to harvest Elijah’s organs, his parents objected to the retrieval of his organs.²⁰¹ In support of their position, Elijah’s mother asserted that when her son agreed to become a donor “her son did not understand what he was signing when he signed his license, and that his signature did not reflect an informed decision.”²⁰² Subsequent litigation concluded in the OPO’s favor to permit the harvesting of Mr. Smith’s organs in

194 *Id.*

195 *Id.*

196 *Id.*

197 *Id.*

198 W. J. Chon et al., *When the Living and the Deceased Cannot Agree on Organ Donation: A Survey of US Organ Procurement Organizations (OPOs)*, 14 AM. J. TRANSPLANTATION 172, 172 (2014).

199 *Id.*, *supra* note 36, at 369.

200 *Id.*

201 *Id.*

202 *Id.*; see also *Columbus Man’s Organs Donated Despite Mom’s Plea*, 10 WBNS (July 11, 2013), <https://www.10tv.com/article/news/crime/crime-tracker/columbus-mans-organs-donated-despite-moms-plea/530-73a83da6-2517-42ac-be96-92fdadce3c22>.

accordance with his driver's license designation but in contravention of his family's wishes.²⁰³

While in many cases OPOs will uphold the donor's decision despite family objections, others may opt not to procure under such circumstances out of deference to the family or to avoid litigation or "negative publicity."²⁰⁴ Where families object, "there is a well-documented practice of medical staff adhering to the wishes of surviving family members to refuse donation even if the deceased previously consented" and "even where an individual has given her legally binding consent to being an organ donor, organs will not be retrieved in the face of opposition by the family."²⁰⁵ Although UAGA makes clear that first-person authorization to donate cannot be overridden, OPOs do not always challenge a family that opposes donation.²⁰⁶

Recent regulatory developments, however, are likely to lead OPOs to resist the family veto. OPOs are facing increased pressure to procure higher numbers of organs. New regulations from the Centers for Medicare & Medicaid Services ("CMS") seek "to increase the supply of lifesaving organs available for transplant in the United States" by "making sure OPOs are performing at optimal levels."²⁰⁷ Under the new CMS regulations designed to combat the continued organ shortage,

203 Misti Crane, *Dispute Over Organ Donation Brings Attention to Defining Death*, COLUMBUS DISPATCH (July 22, 2013), <https://www.dispatch.com/story/lifestyle/faith/2013/07/22/dispute-over-organ-donation-brings/23321596007/>.

204 See Heather M. Traino & Laura A. Siminoff, *Attitudes and Acceptance of First Person Authorization: A National Comparison of Donor and Nondonor Families*, 74 J. TRAUMA ACUTE CARE SURGERY 294, 294–96 (2013); Havekost, *supra* note 2, at 705–06, 710 ("[A] study analyzing data on organ-donation consent rates between 2008 and 2011 found that in three percent of cases (1,080 deaths), eligible donors' families were not asked to donate the decedent's organs."); W. J. Chon et al., *When the Living and the Deceased Cannot Agree on Organ Donation: A Survey of US Organ Procurement Organizations (OPOs)*, 14 AM. J. TRANSPLANTATION 172, 174 (2014).

205 Young, *supra* note 56, at 235.

206 Havekost, *supra* note 2, at 710 ("OPOs have employed diverse tactics to implement first-person-authorization statutes . . . but a significant number of registered donors' wishes are still not followed. . . . [A]s of 2013, . . . twenty percent of OPOs still had not procured an organ when the next of kin objected, and thirty-five percent reported they had yet to 'proceed with organ procurement from a registered organ donor whose family objected to donation.'"); Chon et al., *supra* note 199, at 173–74.

207 Ctrs. for Medicare & Medicaid Servs., *CMS Finalizes Policy that Will Increase the Number of Available Lifesavings Organs by Holding Organ Procurement Organizations Accountable through Transparency and Competition*, CTRS. MEDICARE & MEDICAID SERVS. NEWSROOM (Nov. 20, 2020), <https://www.cms.gov/newsroom/press-releases/cms-finalizes-policy-will-increase-number-available-lifesavings-organs-holding-organ-procurement>.

OPOs must meet certain “outcome measures” for procuring organs, to comply with Medicare and Medicaid reimbursement rules.²⁰⁸ OPOs with “lower than expected organ yield”²⁰⁹ whose procurement numbers fall below certain defined standards will be required to “identify opportunities for improvement and implement changes that lead to improvement in these measures.”²¹⁰ Failure to address low donation rates may place an OPO at risk of losing its certification and the ability to seek reimbursement under Medicare for its organ procurement services.²¹¹ The increased pressures on OPOs to meet performance measures are thus likely to result in an increasingly aggressive pursuit of organs by OPOs. The potential for conflict and family distress is also thus likely to become increasingly common as DCD rates increase and OPOs are incentivized and become more insistent in their pursuit of organs to meet the outcome measures mandated by CMS regulations.

Legislative and regulatory efforts like the new CMS regulations seek to ensure that every hospital death will potentially yield organs suitable for donation and undoubtedly serve to benefit many vulnerable donees in need of lifesaving organs.²¹² These aggressive legislative techniques in pursuit of organs must be balanced with efforts to prepare

208 See 42 C.F.R. § 486.318 (2023) (describing “outcome measures” for organ procurement/organ yield that OPOs must meet); Barry Massa, *How are Organ Procurement Organizations Funded*, LIFECENTER, <https://lifepassiton.org/organ-procurement-organizations-funded/#:~:text=For%20organ%20donation%2C%20OPOs%20are,to%20LifeCenter%20for%20our%20costs> (last visited Dec. 4, 2023) (“For organ donation, OPOs are reimbursed from the transplant hospital receiving the organ. Ultimately, it is the transplant recipient’s insurance who reimburses the hospital for the transplantation procedure. Including [sic] in the reimbursement to the hospital, is the reimbursement to LifeCenter for our costs. Primarily, transplants are reimbursed through Medicare.”).

209 42 C.F.R. § 486.318 (2023).

210 *Id.* § 486.348 (“The OPO must develop, implement, and maintain a comprehensive, data-driven [Quality Assessment and Performance Improvement] program designed to monitor and evaluate performance of all donation services, including services provided under contract or arrangement.”).

211 See *id.* § 486.301 (identifying “requirements that an organ procurement organization (OPO) must meet to have its organ procurement services to hospitals covered under Medicare and Medicaid”); *id.* § 486.316; Ozge Ceren Ersoy et al., *A Critical Look at the U.S. Deceased-Donor Organ Procurement and Utilization System*, 68 NAVAL RSCH. LOGISTICS 3, 19 (2021); Ctrs. for Medicare & Medicaid Servs., *Organ Procurement Organization (OPO) Conditions for Coverage Final Rule: Revisions to Outcome Measures for OPOs CMS-3380-F*, CTRS. MEDICARE & MEDICAID SERVS. NEWSROOM (Nov. 20, 2020), <https://www.cms.gov/newsroom/fact-sheets/organ-procurement-organization-opo-conditions-coverage-final-rule-revisions-outcome-measures-opos>.

212 See 42 U.S.C. § 274(b)(2).

and protect every member of the public impacted by them whose organs could be subject to retrieval. Otherwise, continued legal challenges are to be expected as families and surrogates naturally seek to safeguard and protect their vulnerable loved ones at the end of life.²¹³

V. EQUIPPING THE PUBLIC FOR THE ORGAN DONATION CHOICE

A. Early Intervention to Help Clients Consider Organ Donation Issues

“The best-known way to prevent [family] conflict . . . is for families to discuss organ donation before any tragedy occurs.”²¹⁴ Family disagreement or refusal to consent dramatically decreases when a family has had prior conversations with the decedent about organ donation after death and “the intentions of family members are fully understood by all.”²¹⁵ The more prepared individuals are to make decisions about organ donation and share that decision with family, the less likely conflict and discord are to occur. Conversely, when forced to decide whether to donate organs in high-pressure conditions, families with limited knowledge or no knowledge at all about their loved one’s organ donation wishes are likely to make assumptions and potentially to regret the decision to donate.²¹⁶

A family’s “awareness of their loved ones’ donation wishes is strongly associated with honoring those wishes.”²¹⁷ Where families are prepared in advance, the organ donation process can become less

213 See Whittney H. Darnell et al., *Exploring Family Decisions to Refuse Organ Donation at Imminent Death*, 30 QUALITATIVE HEALTH RSCH. 572, 575–76 (2020) (reporting patient desire to protect the patient as a common reason for refusal to donate).

214 Thomas G. Peters, Commentary, *Family Disagreement Over Organ Donation*, 7 AMA J. ETHICS, 581, 584 (2005).

215 *Id.*

216 Laura A. Siminoff et al., *The Process of Organ Donation and its Effect on Consent: Process of Organ Donation*, 15 CLINICAL TRANSPLANTATION 39, 39 (2001); see also Nancy Kentish-Barnes et al., *A Narrative Review of Family Members’ Experience of Organ Donation Request After Brain Death in the Critical Care Setting*, 45 INTENSIVE CARE MED. 331, 335 (2019); Traino & Siminoff, *supra* note 205, at 298 (For families that were unaware of the decedent’s decision to donate, “[t]he most commonly cited complaints were the timing (e.g., being told right after patient was declared brain dead or before being informed of the patient’s condition) and mode (e.g., emergency medical technicians) of delivery and requesters’ communication of the information. [Some] families noted that the information added to their stress because of lack of family communication regarding the patient’s donation wishes, the family’s position against organ donation, and the use of life supports to maintain the patient for donation purposes.”).

217 Kentish-Barnes et al., *supra* note 217, at 335.

emotionally traumatic.²¹⁸ Preparation for and decision-making about organ donation in advance may thus help to alleviate the emotional strain placed on families when organ donation is considered for the first time in the hospital setting upon the death of a loved one.²¹⁹

To better equip families to consider and reflect on such decisions before a health crisis occurs, and to relieve the trauma that can attend such requests, the legal profession should help to disseminate information and resources to their clients about the potential repercussions of the organ donation decision. Such outreach and preparation would help combat a potential lack of preparedness by encouraging the public to think about organ donation well in advance of a medical crisis; to seek the advice and counsel of religious advisors, family, and physicians; and to share and record their organ donation wishes. Given that a family's knowledge of the decedent's wishes increases the likelihood that those wishes will be honored, it is critical for legal professionals to help to bridge the gap between their clients and their clients' families in advance of a medical crisis. Attorneys can reduce the likelihood of their clients' donation wishes being unknown or disregarded by proactively encouraging their clients to make and share their organ donation wishes by providing reliable and comprehensive information about donation to allow clients to make an informed choice, and by assisting their clients in communicating their wishes to their family members.

Moreover, early intervention to help clients consider organ donation in advance will have the effect of increasing the availability of organs for those in need by helping and encouraging clients to make informed decisions and to share those donation decisions with family. Indeed, "[t]he strongest and most consistent predictor of donation authorization is knowledge or awareness of the donor-eligible patient's wishes."²²⁰ Where families have discussed donation with the potential donor, the likelihood of family members agreeing to donate increases as much as six-fold.²²¹ "[F]amilies are more likely to donate if they are prepared that a request will be made; conversely, families who reported greater surprise were less likely to donate."²²² When faced with an organ donation decision, "the family's knowledge of the patient's previous

218 *See id.*

219 *See* Chon et al., *supra* note 199, at 176 (in 2005, at the time of the last national survey on organ donation, only 53% of Americans reported that a family member had communicated their wishes about donation).

220 Kentish-Barnes et al., *supra* note 217, at 335.

221 Chon et al., *supra* note 199, at 172.

222 Laura A. Siminoff, *Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation*, 286 JAMA 71, 76 (2001).

wishes is central to decision making.”²²³

B. Medical-Legal Community Partnerships

The benefit of medical-legal partnerships as instrumental in addressing varied public health needs is well recorded.²²⁴ Harnessing the power of such partnerships toward discreet projects can enhance their impact. Joint medical-legal teams should work together to address pertinent organ donation questions and concerns of importance to the public as well as help disseminate accurate and reliable information to the public. For example, medical-legal teams working together to create free informational resources to improve organ donation literacy can better equip the public to make organ donation decisions. The collaborative creation of such informational materials would serve to not only educate lawyers but also the clients whom they serve. Resources like this, disseminated through national and local bar associations, and in turn shared by legal professionals with clients, would increase the likelihood that members of the public are aware of the potential implications of their organ donation decision before a crisis occurs.²²⁵ Direct outreach of this nature would serve to increase the availability of reliable information from trusted sources.

Similarly, interdisciplinary medical-legal teams might work together to create state-specific organ donation advance directive or consent forms that allow for greater consideration of the implications of the donation decision.²²⁶ Given arguments that driver’s license centers or

223 Laura A. Siminoff et al., *Public Policy Governing Organ and Tissue Procurement in the United States: Results from the National Organ and Tissue Procurement Study*, 123 ANNALS INTERNAL MED. 10, 16 (1995).

224 Yael Zakai Cannon, *Medical-Legal Partnership As a Model for Access to Justice*, 75 STAN. L. REV. ONLINE 73, 80 (2023).

225 Kathy L. Cerminara, *Therapeutic Jurisprudence’s Future in Health Law: Bringing the Patient Back into the Picture*, 63 INT’L J.L. & PSYCH.. 56, 60 (2019) (“[M]edical-legal partnership[s] (MLP) provide[] attorneys with opportunities to engage in preventive lawyering and potentially proactively assist in better patient health outcomes.”).

226 Moorlock & Draper, *supra* note 37, at 1 (arguing that “[i]n order to be confident that a patient would really wish to go ahead with the various interventions and procedures that now accompany organ donation, more nuanced information than a simple ‘yes’ or ‘no’ may be required. This is of particular importance for donation after circulatory death, where some interventions to facilitate donation occur when the patient is still alive” and proposing “the implementation of an online form to allow people to record more nuanced wishes in relation to donation, including an indication of competing wishes and how these should be weighed into decision-making”).

organ donation registries do not meaningfully provide potential donors with adequate information, more comprehensive organ donation forms created by medical-legal teams would allow clients to consider more thoroughly some of the implications of their organ donation decision. Such forms could then be used by legal professionals preparing end-of-life plans to help clients meaningfully reflect and combat misinformation.

Involving the legal profession preemptively may help families before disputes devolve into litigation by encouraging clients to preemptively consider and plan for the organ donation decision. Recent estimates indicate that 33% of U.S. adults have created an estate plan.²²⁷ For any fraction of these adults who prepared their plans with an estate planning attorney, the capacity of those attorneys to share meaningful, balanced, organ donation planning information with the public is immense, and the potential impact on public health could be profound.²²⁸ Yet “[c]urrently, communication between physicians, lawyers, patients and family members regarding goals for end-of-life care, and for organ and tissue donation after death, is inconsistent at best.”²²⁹ Targeted medical-legal collaborations that bridge the knowledge gap for those considering organ donation and encourage discussion of that decision with family stakeholders and decision-makers can help to alleviate some of the conflict that can occur when such decisions are not meaningfully considered in advance.

Including a professional education component in the form of joint medical-legal trainings on organ donation issues can serve to foster further collaboration across silos and enhance and enrich the expertise of all involved. Through joint continuing legal education and continuing medical education trainings about organ donation considerations and disputes, both professions can benefit from each other’s knowledge to provide more meaningful service to the public.

In addition to enriching and improving lawyer-client end-of-life planning services, interdisciplinary collaborations would be beneficial to medical professionals. Although physicians themselves are urged to have conversations with their patients about organ donation in advance of a medical crisis, they may instead be inclined to “avoid[] the all-round discomfort of raising the topic for the first time in end-of-life

227 Lorie Konish, *67% of Americans Have No Estate Plan*, CNBC (Apr. 11, 2022), <https://www.cnbc.com/2022/04/11/67percent-of-americans-have-no-estate-plan-heres-how-to-get-started-on-one.html>.

228 See Bern-Klug & Byram, *supra* note 26, at 4.

229 Parent, *supra* note 182, at 35.

situations.”²³⁰ Physicians may be reluctant to initiate the organ donation discussion with their patients for fear of being perceived as harboring ulterior motives related to procuring organs, or not having the patient’s best interests at heart. “[A]sking patients about organ donation seems to violate . . . the ethical commitment to consider the patient’s health as the primary concern.”²³¹ A physician who initiates the organ donation discussion risks alienating the patient who suspects that the physician no longer has the patient’s health and wellbeing as a priority, potentially damaging physician-patient trust. Legal professionals, however, do not face similar risks—and those they do face are not of the same magnitude—when raising the organ donation question with clients. Having legal professionals encourage their clients to take the first step and raise or initiate the organ donation discussion with their physician may help ease the discomfort of having physicians initiate such conversations themselves.²³²

Community-oriented medical-legal partnerships also have the potential to assist disadvantaged communities that may not have access to meaningful information about organ donation decisions. Given that “organ donation registration rates are inversely associated with concentrated disadvantage” and “the greater the concentrated disadvantage at the ZIP code level, the lower the organ donation registration rate.” Such community initiatives in disadvantaged, often Black neighborhoods have the potential to help address these disparities.²³³ Moreover, among racial minorities, historically low organ donation rates negatively affect minority patients in need of transplants, considering that some genetic details such as blood type

230 Kao, *supra* note 16, at 1 (“Primary care physicians should discuss the option of organ donation as part of routine patient visits.”).

231 *Id.*

232 Cerminara, *supra* note 226, at 60.

Traditionally, lawyers representing clients with medical problems have done so in settings divorced from the operation of the medical system. Other than dealing with medical professionals as defendants or as supporting or opposing expert witnesses, plaintiffs’ lawyers, at least, did not view themselves as part of any medical team. During medical school, in fact, many physicians are inculcated with an anti-lawyer/anti-law attitude counseling against teaming up with any attorney. Such a view on the part of physicians is counterproductive because lawyers can be physicians’ best friends.

Id.

233 Enbal Shacham et al., *Determinants of Organ Donation Registration*, 18 AM. J. TRANSPLANTATION 2798, 2802 (2018).

and other factors relevant to transplants have been found to correlate with race.²³⁴ Low donation rates in Black communities may stem from a “deep distrust of the health care system,” which stems from “injustices [that] have been pervasive for generations.”²³⁵ The infrequency of end-of-life planning among Black Americans is induced by additional factors as well, with Black scholars citing considerations that include “a strong faith in God, a reliance on loved ones for making important decisions, and a deference to elders who may feel uncomfortable discussing such matters,” in addition to concerns that “Black Americans often have limited knowledge about what ought to be included in conversations about advance care planning.”²³⁶

Although refusal to donate is a personal choice to be respected, education and information to help the public make fully informed decisions about organ donation would benefit those who otherwise may not have access to accurate information about organ donation choices. Considered and thoughtful medical-legal and community partnerships have the potential to help prospective donors and their families better understand the implications of the donation decision, help to ensure that the wishes of those who do wish to donate are honored and upheld, and perhaps also help to address the critical organ shortage that annually results in immense loss of life. Of course, any such collaboration must be entered into and offered with humility and sensitivity to the populations served, and with the inclusion of community partners to effectively and respectfully identify and address barriers to donation.²³⁷

234 Amber B. Kernodle et al., *Examination of Racial and Ethnic Differences in Deceased Organ Donation Ratio Over Time in the US*, 156 JAMA SURGERY, April 2021, at 1, 2 (“Relatively lower rates of deceased organ donation from minority populations not only affect the general supply of organs for transplant but have important implications on long-standing racial disparities among wait-listed candidates. For example, wait-listed candidates with blood type B, who are mostly racial/ethnic minority groups, have the longest wait times and receive fewer transplants than candidates with other blood types. Similar scenarios are seen in organs where human leukocyte antigen matching (which is correlated with race) is an allocation priority. Thus, increasing minority representation in the deceased donor pool is particularly relevant for minority individuals on the waiting list.” (footnotes omitted)).

235 Maisha T. Robinson, *Family, Fear, and Faith: Helping Black Patients with End-of-Life Decisions*, ASS’N AM. MED. COLLS. (July 12, 2022), <https://www.aamc.org/news-insights/family-fear-and-faith-helping-black-patients-end-life-decisions>.

236 *Id.*

237 See, e.g., Karen Bouffard, *How a Surgeon Helped Solve the Problem of Far too Few Black Organ Donors*, USC ANNENBERG CTR. HEALTH JOURNALISM NEWSL. (Aug. 6, 2018), <https://centerforhealthjournalism.org/2018/08/03/how-surgeon-helped-solve-problem-far-too-few-black-organ-donors> (discussing five barriers to African

CONCLUSION

The organ donation choice involves highly personal moral, social, ethical, cultural, and religious considerations, which well-trained attorneys are called upon to help the client reconcile and record. Such matters can be difficult to broach with a client, and may require difficult or uncomfortable discussions concerning life, death, and the human body, which lawyers may be hesitant to raise. However, this discomfort does not absolve lawyers of their obligations, as “[l]egal advice often involves unpleasant facts and alternatives that a client may be disinclined to confront,” and “a lawyer should not be deterred from giving candid advice by the prospect that the advice will be unpalatable to the client.”²³⁸ Failure to help the client evaluate and reflect on their organ donation choices risks leaving clients and their families unprepared for the future, undermining the lawyer’s goal of helping clients prepare for a good death.²³⁹

Organ donation decisions, which affect families at their most vulnerable, implicate ancient rituals of grief, mourning, and respect for the dead and dying. The counsel provided to clients grappling with such questions extends far beyond the scope of pure legal issues. Yet the practice of law often requires practitioners to “go beyond the legal issues” and counsel clients on “non-legal” matters that affect the physical, mental, and emotional welfare of clients and their families.²⁴⁰ Adequate training and resources, together with the advice and assistance

American donation as including (i) lack of awareness “of the great need for organ donation within their own community,” (ii) fear that organ donation contradicted religious beliefs, (iii) “deep distrust of health care providers,” (iv) fear that if they consented hospitals would “allow them to die so their organs could be harvested,” and (v) concern that “doctors only wanted their organs so they could be transplanted into white people”); *see also* Robinson, *supra* note 236.

238 MODEL RULES PRO. CONDUCT r. 2.1 cmt. 1 (AM. BAR ASS’N 1983); *see also* Sneddon, *supra* note 240, at 302 (“It has been stated that ‘[t]he most important dimension in all of this [estate planning] is not litigation or taxes or even property distribution; it is counseling.’”).

239 Larry O. Natt Gantt II, *More Than Lawyers: The Legal and Ethical Implications of Counseling Clients on Nonlegal Considerations*, 18 GEO. J. LEGAL ETHICS 365, 365 (2005); *see* Karen J. Sneddon, *Dead Men (and Women) Should Tell Tales: Narrative, Intent, and the Construction of Wills*, 46 AM. COLL. TRS. & ESTS. COUNS. L.J. 239, 302 (2021) (“Estate planning ‘cannot be fulfilled with a fill-in-the-blanks system of will interviews, and lawyers who insist on operating their wills practice as if they were taking driver-license applications should get into another line of work.’”); *see also* Paul Fisher, *The Power Tools of Estate Conflict Management Recharging the Culture of Estate Conflicts, Part 2*, PROB. & PROP., July/August 2010, at 42, 43, 46.

240 Gantt II, *supra* note 239, at 365.

of medical, ethical, religious, or cultural experts and community partners can help to better equip lawyers for such client conversations. By sensitively engaging in the difficult conversations about complex-yet-important end-of-life matters outlined in this article, the legal profession can help to reduce the potential for conflict and uncertainty at the end of life and ease the distress that can occur when organ donation is not meaningfully considered.