# PRESUMED CONSENT TO ORGAN DONATION: ITS RISE AND FALL IN THE UNITED STATES

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As the gap between the need for organ transplants and the supply of organs has increasingly widened, many scholars have urged the adoption of "presumed consent" to organ donation. Under a presumed consent regime, the state would assume that a person agreed to organ donation after death unless the person (or a family member) had lodged an objection to posthumous organ donation. Such an assumption would reverse existing law—currently, it is generally the case that organ donation requires actual consent from the donor or a family member of the donor.

For some forty years in a little-known experiment, the United States tried presumed consent on a limited basis. In many states, when dead persons came under the custody of coroners or medical examiners, those officials could authorize cornea donation—or even organ donation—in the absence of a known objection to the donation by the decedent or a family member. However, in 2006, the Revised Uniform Anatomical Gift Act recommended against presumed consent, and most states have followed its lead.

This Article reviews the history of presumed consent in the United States and concludes that presumed consent failed because it could not overcome the major reason why people do not become organ donors after death—the refusal of family members to give consent to donation. To the extent that presumed consent allowed family members to overcome the presumption and withhold consent, it did not address the reasons why family members say no. To the extent that professionals tried to preserve the presumption by bypassing families, they validated fears that doctors will be too quick to take organs from dead persons who would not have wanted their organs removed. The United States's history with presumed consent indicates that other proposed reforms will be needed to address the shortage of organs for transplantation.

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#### INTRODUCTION

Proponents of "presumed consent" to organ donation have always faced an uphill battle. In supporting a presumption that people want to donate their organs after death—and a policy of organ removal in the absence of an objection by decedents or their family—advocates push a policy that goes against the grain of American individualism and is more at home in countries with a stronger communitarian ethic.<sup>1</sup> Presumed consent also raises the specter of one of society's deepest fears—that unscrupulous doctors will take a person's heart, liver, kidneys, or other organs against the person's wishes, or even hasten a person's death to obtain the organs. Consider in this regard the resonance of Robin Cook's *Coma*,<sup>2</sup> the best-selling thriller in

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<sup>1.</sup> Presumed consent laws, in fact, are common in Western European countries like Austria, Belgium, France, Italy, and Sweden. Steve P. Calandrillo, *Cash for Kidneys? Utilizing Incentives to End America's Organ Shortage*, 13 GEO. MASON L. REV. 69, 125-26 (2004); see also Anke Janssen & Sjef Gevers, *Explicit or Presumed Consent and Organ Donation Post-Mortem: Does It Matter?*, 24 MED. & L. 575, 578 (2005).

<sup>2.</sup> ROBIN COOK, COMA (1977).

which doctors put patients into a coma so their organs could be removed for transplantation, or a popular episode of the television series, *Law & Order*, in which a man was kidnapped and left in a park after his kidney was taken.<sup>3</sup>

While the United States has tried presumed consent on a very limited basis for roughly four decades, recent developments in the law suggest that even this highly limited use is being abandoned. Presumed consent appears to have failed because it went either too far or not far enough. It did not go far enough to the extent that family members were allowed to overcome the presumption that the dead person favored donation. By permitting families to reject donation, presumed consent did not address the major reason why people do not become organ donors after death—the refusal of family members to give consent. On the other hand, presumed consent went too far to the extent that public officials bypassed family members and avoided the possibility that they would refuse consent. Such action only validated fears that the desire for more organs for transplantation would result in organs being taken from dead persons who would not have wanted their organs removed.

Presumed consent, in short, faced a Catch-22. If implemented in a way that was acceptable to the public, it could not solve the organ shortage. If implemented in a way that might alleviate the organ shortage, it became unacceptable to the public.

To be sure, presumed consent was designed to address a serious shortfall in transplantable organs in the United States. Each year, thousands of Americans receive the "gift of life" when they undergo transplant surgery. Donor hearts, lungs, livers, and kidneys save people when their own organs have failed and they face a shortened lifespan, if not imminent death.<sup>4</sup> At the same time, however, many more people wait for a life-saving organ transplant, and thousands of individuals die while waiting. Nearly 100,000 people are on a wait list for an organ in the United States, but fewer than 30,000 organs are transplanted each year, and more than 6000 people die every

<sup>3.</sup> Law & Order: Sonata for a Solo Organ (NBC television broadcast Apr. 2, 1991); see also Joe Morgenstern, A Script Recipe: One Kidney, Lots of Writers, Beat Well, N.Y. TIMES, Mar. 31, 1991, at B25 (describing the writing of the script for the episode). Kidney theft is a common urban myth in the United States. JAN HAROLD BRUNVAND, ENCYCLOPEDIA OF URBAN LEGENDS, 227-28 (2002).

<sup>4.</sup> Kidneys may not seem to be life-saving given the availability of dialysis to provide artificial kidney function. However, life expectancy is longer for persons who receive a kidney transplant than for persons who remain on dialysis. Gabriel C. Oniscu et al., *Impact of Cadaveric Renal Transplantation on Survival in Patients Listed for Transplantation*, 16 J. AM. SOC. NEPHROLOGY 1859, 1862 (2005). One study found a tripling of life expectancy with a transplant. *Id.* at 1859, 1864 (reporting life expectancy with dialysis at less than six years compared with more than seventeen years with a transplant).

year while waiting for a transplant.<sup>5</sup> Moreover, the gap between need and supply grows larger every year. Between 1988 and 2006, the number of transplants more than doubled, but the wait list grew roughly six-fold.<sup>6</sup>

The gap between need and supply need not be so large. According to conservative estimates, roughly twice as many organs would be available each year if consent to donation were obtained for every person who dies and whose organs are viable for transplantation.<sup>7</sup> Many of these persons would have wanted to donate their organs, but consent was not obtained. People often do not consider the question of posthumous donation while still alive, physicians may fail to ask family members for surrogate consent, or family members withhold consent to donation even when the dead person would have preferred to be a donor.

To capture the organs that could be transplanted but are lost for lack of consent, many scholars have urged broad adoption of presumed consent to donation.<sup>8</sup> Under a presumed consent regime, the state would assume that a dead person has consented to the posthumous donation of organs unless an objection has been lodged either by the person while alive or by a family member after the person's death.<sup>9</sup> Such a presumption would reverse the law's existing

8. Arthur L. Caplan, Organ Transplants: The Costs of Success, 13(6) HASTINGS CENTER REP. 23, 27-28 (1983); Jesse Dukeminier, Jr. & David Sanders, Organ Transplantation: A Proposal for Routine Salvaging of Cadaver Organs, 279 NEW ENG. J. MED. 413, 416-19 (1968); Michael B. Gill, Presumed Consent, Autonomy, and Organ Donation, 29 J. MED. & PHILOSOPHY 37, 37-38 (2004); James L. Muyskens, An Alternative Policy for Obtaining Cadaver Organs for Transplantation, 8 PHILOSOPHY & PUB. AFF. 88, 98-99 (1978); see also Theodore Silver, The Case for a Post-Mortem Organ Draft and a Proposed Model Organ Draft Act, 68 B.U. L. REV. 681, 681 (1988) (proposing legislation that would empower the state to take organs for transplantation after a person's death, with objections to removal recognized only when based on religious belief).

9. There is some dispute about terms in the debate over presumed consent. As some have argued, it is misleading to characterize these statutes as "presuming

<sup>5.</sup> DAVID ORENTLICHER ET AL., BIOETHICS AND PUBLIC HEALTH LAW 356-57 (2d ed. 2008).

<sup>6.</sup> *Id.* at 357.

<sup>7.</sup> Francis L. Delmonico et al., Organ Donation and Utilization in the United States, 2004, 5 AM. J. TRANSPLANTATION 862, 863 tbl.1 (2005) (reporting 12,031 eligible deceased donors and 6630 consents for donation in the United States in 2003); Ellen Sheehy et al., Estimating the Number of Potential Organ Donors in the United States, 349 NEW ENG. J. MED. 667, 671 (2003) (reporting that less than half of eligible donors became donors). Other estimates suggest that organ transplants could more than quintuple if all usable organs were transplanted. COMM. ON INCREASING RATES OF ORGAN DONATION, ORGAN DONATION: OPPORTUNITIES FOR ACTION 6, 127 (James T. Childress & Catharyn T. Liverman eds., 2006) (estimating as many as 16,800 potential donors from brain death and another 22,000 potential donors from persons who die from cardiac arrest).

presumption. For the most part, laws in the fifty states assume a person has not consented to organ donation in the absence of actual consent by the person or by a family member.<sup>10</sup> In other words, presumed consent would replace an "opt-in" system for organ donation with an "opt-out" system.<sup>11</sup> Instead of placing the burden on health care professionals to obtain consent, the burden would be on individuals and their families to document their objections.

While the law has generally eschewed presumed consent, many states employed presumed consent on a limited basis for a number of years. Starting in the late 1960s, states began to authorize retrieval of corneas and other eye tissues,<sup>12</sup> pituitary glands, and sometimes any tissues or organs (including hearts, lungs, livers, and kidneys) from dead persons who came under the custody of coroners or medical examiners.<sup>13</sup> Since these people would be undergoing an autopsy to determine the cause of death, their bodies already would be subjected to a major intrusion.<sup>14</sup> Retrieving some tissues or organs

consent" of donors. Rather, according to this view, the laws really are routine retrieval or routine salvaging statutes that ignore considerations of a person's intent unless the person—or a family member—actually expresses an unwillingness to donate. R.M. Veatch & J.B. Pitt, *The Myth of Presumed Consent: Ethical Problems in New Organ Procurement Strategies*, 27 TRANSPLANTATION PROCEEDINGS 1888, 1888 (1995). Some proponents of presumed consent use the routine retrieval or routine salvaging language. Dukeminier & Sanders, *supra* note 8, at 416, 418-19. Another term used for some of these statutes is "legislative consent." Michele Goodwin, *Rethinking Legislative Consent Law*?, 5 DEPAUL J. HEALTH CARE L. 257, 272-73 (2002).

The different terms reflect the fact that different approaches are possible besides a requirement of explicit consent. COMM. ON INCREASING RATES OF ORGAN DONATION, *supra* note 7, at 209-12. One can presume consent but allow either the decedent or a family member to overcome the presumption. *Id.* at 210-11. Or, one could allow only the decedent to overcome the presumption of consent. *Id.* If the family is permitted to overcome the presumption, then the law could either require that doctors consult with the family or only require doctors to take account of objections of which they are aware. *Id.* at 211. Finally, the law could call for routine removal of organs, regardless of the decedent's or family's wishes, with an exception for objections based on religious beliefs. *Id.* 

<sup>10.</sup> See infra notes 19-21 and accompanying text.

<sup>11.</sup> Id.

<sup>12.</sup> Although corneas are technically tissues, organ donation law typically characterizes them as organs. Julia D. Mahoney, *The Market for Human Tissue*, 86 VA. L. REV. 163, 184 (2000). An organ is a relatively independent part of the body that carries out specific functions (e.g., eye, heart, lung, liver, kidney, pancreas, stomach). Each organ is composed of several tissues that perform the organ's functions. An eye has a cornea, a lens, a retina, and other tissues, for example.

<sup>13.</sup> See id. at 176-77. An early proposal for presumed consent came from David Sanders & Jesse Dukeminier, Jr., Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation, 15 UCLA L. REV. 357, 410-13 (1968).

<sup>14.</sup> Interestingly, some state statutes authorized presumed consent only when an autopsy was being performed, while other state statutes authorized presumed consent when the decedent was under the custody of a coroner or medical examiner. *Compare* 

at the same time to provide great benefit to living persons had an obvious attraction to lawmakers.

Under these presumed consent statutes, coroners or medical examiners could authorize the donation of the tissues or organs as long as they were not aware of an objection by the person or a family member.<sup>15</sup> The 1987 Uniform Anatomical Gift Act (1987 UAGA) reinforced this trend in presumed consent statutes when it recommended presumed consent for the donation of any organ or tissue from cadavers under the custody of coroners or medical examiners.<sup>16</sup> At one time or another, more than two-thirds of the states adopted presumed consent statutes.<sup>17</sup>

However, the 2006 Revised Uniform Anatomical Gift Act (2006 UAGA) has eliminated the presumed consent provisions of the 1987 UAGA and now recommends retrieval of corneas, other tissues, and organs only when there is actual consent by the dead person or by a family member of the decedent.<sup>18</sup> States have quickly taken up the 2006 UAGA, with thirty-three states and the District of Columbia passing the 2006 UAGA in either 2007 or 2008.<sup>19</sup> To be sure, some of those states have retained presumed consent at least for corneas if not for organs,<sup>20</sup> but we are now seeing a major retrenchment in the

16. UNIF. ANATOMICAL GIFT ACT § 4 (1987).

17. Goodwin, supra note 9, at 274-75, 278 (recognizing passage in twenty-eight states); see also ALA. CODE § 22-19-54 (LexisNexis Supp. 2005); IND. CODE ANN. § 29-2-16-1 (West 1994 & Supp. 2008); IOWA CODE § 142C.4A (West 2005 & Supp. 2008); MINN. STAT. ANN. § 525.9213 (West 2002 & Supp. 2008); N.H. REV. STAT. ANN. § 291-A:5 (1999); N.M. STAT. ANN. § 24-6A-4 (LexisNexis 2000); OR. REV. STAT. ANN. § 97.956 (West 2002 & Supp. 2008). Despite the authorization to take organs in the absence of an objection, presumed consent statutes have been used much more regularly with corneas and other eye tissues than to retrieve hearts, lungs, livers, or kidneys. See Goodwin, supra note 9, at 266. For the most part, transplant programs are not comfortable using organs without actual consent. See, e.g., id. at 275-76.

18. REV. UNIF. ANATOMICAL GIFT ACT § 8 (2006).

19. National Conference of Commissioners on Uniform State Laws, Uniform Anatomical Gift Act (2006), Enactment Status Map, http://www.anatomicalgiftact.org/DesktopDefault.aspx?tabindex=2&tabid=72 (last visited Apr. 6, 2009). In 2009, as this Articles goes to press, the 2006 UAGA has been enacted in a thirty-fourth state, has passed both houses in another state, and is being considered in six more states. Id.

20. See, e.g., IND. CODE ANN. § 36-2-14-19 (West 2006 & Supp. 2008) (corneas); N.C. GEN. STAT. § 130A-412.3 (2008) (corneas); WIS. STAT. ANN. § 157.06 (West Supp.

ALA. CODE § 22-19-54 (LexisNexis Supp. 2005) (autopsy not required), *with* MD. CODE ANN., EST. & TRUSTS § 4-509.1 (LexisNexis 2001) (autopsy required). Since coroners and medical examiners do not autopsy everyone under their custody, it is possible for organs to be taken in the absence of an autopsy.

<sup>15.</sup> See, e.g., MINN. STAT. ANN. § 525.9213 (West 2006) (authorizing removal of organs from dead persons under the custody of coroners or medical examiners in the absence of a known objection to donation), *repealed by* Darlene Luther Revised Uniform Anatomical Gift Act, 2007 Minn. Laws, ch. 120, § 26 (codified as MINN. STAT. § 525A.01-25 (2008)).

use of presumed consent in the United States.<sup>21</sup>

This Article reviews the history of presumed consent in the United States and considers the implications of the apparent abandonment of such an approach for increasing the supply of organs for transplantation.

Part I of the Article documents the rise of presumed consent in the United States, Part II discusses the abandonment of presumed consent, and Part III analyzes the reasons why presumed consent is being discarded as a way to address the shortage of organs for transplantation. The Article concludes with observations on the kinds of reforms that would be successful in addressing the organ shortage.

#### I. THE RISE OF PRESUMED CONSENT IN THE UNITED STATES

Presumed consent statutes first appeared in the late 1960s as a way to address the serious shortage of corneas, pituitary glands, and organs for transplantation or other therapeutic uses.<sup>22</sup> Corneas may

22. Among the early states to adopt presumed consent were Hawaii in 1967 (any

<sup>2008) (</sup>organs).

<sup>21.</sup> Georgia, Minnesota, New Mexico, and North Dakota are among the states that have followed the 2006 UAGA in revoking their grants of authority to coroners and medical examiners. GA. CODE ANN. § 31-23-6(b) (2006), repealed by 2008 Ga. Laws 545 § 3 (codified at GA. CODE ANN. § 44-5-140 to -159.4 (2008)); MINN. STAT. ANN. § 525.9213 (West 2006) repealed by 2007 Minn. Laws ch. 120, § 26 (codified at MINN. STAT. § 525A.01-25 (2008)); N.M. STAT. ANN. § 24-6A-4 (LexisNexis 2000), repealed by 2007 N.M. Laws ch. 323, § 35 (codified at N.M. STAT. ANN. § 24-6B-1 to -25 (LexisNexis 2008)); N.D. CENT. CODE § 23-06.2-04 (2002), repealed by 2007 N.D. Laws ch. 237, § 7 (codified in scattered sections of the N.D. CENT. CODE (2007)). Other states include Alabama, Arizona, Arkansas, California, Hawaii, Idaho, Iowa, Oregon, Rhode Island, Utah, Virginia, and West Virginia. ALA. CODE § 22-19-54 (LexisNexis 1997), repealed by 2008 Ala. Laws 453, § 1 (codified at ALA. CODE § 22-19-160 to -181 (LexisNexis 2008)); ARIZ. REV. STAT. ANN. § 36-844 (West 2003), amended by 2007 Ariz. Sess. Laws ch. 281, § 3; ARK. CODE ANN. § 20-17-601 to -613 (LexisNexis 2006), repealed by 2007 Ark. Acts 839, § 6 (codified at ARK. CODE ANN. § 20-17 (LexisNexis 2008)); CAL. HEALTH & SAFETY CODE § 7151 (West 2007), repealed by 2007 Cal. Adv. Legis. Serv. ch. 629, § 2 (codified at CAL. HEALTH & SAFETY CODE § 7150-.40 (West Supp. 2008)); HAW. REV. STAT. ANN. § 327-4 (LexisNexis 2007), repealed by 2008 Haw. Sess. Laws ch. 122, § 54 (codified at HAW. REV. STAT. § 327-4 (2008)); IDAHO CODE ANN. §39-3413 (LexisNexis 2002 & 2005 Supp.), amended by 2007 Idaho Sess. Laws ch. 30, § 2; IOWA CODE 142c.4A (LexisNexis 2002), amended by 2007 Iowa Acts ch. 44, § 5; OR. REV. STAT. § 97.950 (West 2004), repealed by 2007 Or. Laws ch. 681, § 31 (codified at OR. REV. STAT. 97.951-.982 (West Supp. 2008)); R.I. GEN. LAWS § 23-18.6-4 (LexisNexis 2001), repealed by 2007 R.I. Pub. Laws ch. 476, § 1 (codified at R.I. Gen. Laws § 23-18.6.1-1 to -25 (2008)); UTAH CODE ANN. § 26-28-5 (1998), repealed by 2007 Utah Laws 60, § 34 (codified at UTAH CODE ANN., § 26-28-101 to -125 (2008)); VA. CODE ANN. § 32.1-290 (2004), repealed by 2007 Va. Acts 92, § 907 (codified in scattered sections of the VA. CODE ANN. (2008)); W. VA. CODE ANN. § 16-19-1 to -14 (LexisNexis 2001 & Supp. 2005), repealed by 2008 W. Va. Acts 191 (codified at W. VA. CODE ANN. § 16-19-1 to -23 (2008)).

not be life-saving in the way a heart or liver is, but they can restore eyesight in people with injured or diseased corneas, or provide eyesight to infants born without functioning corneas.<sup>23</sup> While corneas and organs are used for transplantation, the pituitary glands were used as a source of growth hormone for medical treatment.<sup>24</sup> Once a synthetic form of growth hormone was developed in 1985, it replaced natural growth hormone because of the risks of transmitting Creutzfeldt-Jakob disease from the donor of the pituitary gland tissue to the recipient of the growth hormone infusion.<sup>25</sup>

With the exception of a California statute that applied to patients in hospitals,<sup>26</sup> the presumed consent statutes limited their application to cadavers under the custody of coroners or medical examiners.<sup>27</sup> Most of the early statutes were restricted to cornea or

25. Creutzfeldt-Jakob disease is a degenerative neurologic disorder, akin to "mad cow" disease, that was diagnosed in patients who had received human growth hormone donations many years earlier. STYNE, *supra* note 24, at 197.

26. Before adopting the 2006 UAGA, California allowed removal of organs in the absence of objection or consent when someone died in the hospital and the hospital was unable to locate a family member, guardian, or health care agent, as long as the hospital made a reasonable effort for at least twelve hours to locate a representative of the decedent. CAL. HEALTH & SAFETY CODE § 7151.5(b) (West 2007).

27. In some jurisdictions, decedents undergoing state-required autopsies are under the custody of a public health officer rather than a coroner or medical examiner. Hence, the 1987 UAGA and many state statutes give public health officers the ability to authorize organ or tissue retrieval. UNIF. ANATOMICAL GIFT ACT § 4 (1987).

In theory, the limitation to coroner or medical examiner cases need not have been limiting. More than half of potential organ donors after death come under the custody of coroners or medical examiners. *See infra* text accompanying note 164. However, many coroners and medical examiners have been reluctant to exercise their authority to employ presumed consent. Goodwin, *supra* note 9, at 274-75 (reporting that coroners and medical examiners in only nine states took tissues or organs on the basis of presumed consent).

tissue) and Virginia in 1968 (any organ). See Jesse Dukeminier, Jr., Supplying Organs for Transplantation, 68 MICH. L. REV. 811, 843 (1970) (describing statute passed in Hawaii in 1967, now codified in the last sentence of HAW. REV. STAT. § 841-14 (2008)); Michael McH. Collins, Note, Organ Transplantation and the Donation: A Proposal for Legislation, 10 WM. & MARY L. REV. 975, 982-83 & n.42 (1969) (citing 1968 Virginia presumed consent statute).

<sup>23.</sup> State v. Powell, 497 So. 2d 1188, 1190-91 (Fla. 1986).

<sup>24.</sup> For people who suffer from a deficiency of growth hormone and experience unusually short stature and other effects, replacement therapy is an important treatment to compensate for the lack of the hormone. See DENNIS STYNE, Growth, in GREENSPAN'S BASIC & CLINICAL ENDOCRINOLOGY 197, 197 (David G. Gardner & Dolores Shoback eds., 8th ed. 2007). Growth hormone also is used to increase the height of children who have normal levels of growth hormone but still are very short, and for other therapeutic purposes unrelated to height. David B. Allen, Growth Hormone Therapy for Short Stature: Is the Benefit Worth the Burden?, 118 PEDIATRICS 343, 343 (2006); Marie Gelato et al., Role of Recombinant Human Growth Hormone in HIV-Associated Wasting and Cachexia: Pathophysiology and Rationale for Treatment, 29 CLINICAL THERAPEUTICS 2269, 2279 (2007).

pituitary gland retrieval, and the impact of the presumed consent statutes was dramatic in some states. Georgia adopted its cornea retrieval statute in 1978, and the number of cornea transplants in the state jumped from 25 in 1977 to 1000 in 1984.<sup>28</sup> Florida enacted its statute in 1977, and cornea transplants increased from 500 in 1975 to 3000 in 1984.<sup>29</sup> Texas saw an increase from an average of 215 cornea transplants a year to more than 1300 transplants a year after adopting its statute in 1977.<sup>30</sup> In Alabama, presumed consent resulted in the state having more corneas than it needed for transplantation.<sup>31</sup>

While potentially very effective, presumed consent statutes are controversial and not universally accepted. In many cities and states, coroners and medical examiners did not exercise their presumed consent authority. This was especially the case with respect to organs, which have rarely been removed by coroners or medical examiners under their presumed consent authority,<sup>32</sup> but often also with respect to corneas. In Kentucky, for example, medical professionals and eye bank officials did not support presumed consent for cornea retrieval, and that state's statute did not achieve the results seen in Georgia, Florida, Texas, or Alabama.<sup>33</sup> Members

33. Goodwin, *supra* note 9, at 275-76. The lack of support reflected not only concerns about individual autonomy but also about the need to obtain a medical history of the donor from the next of kin. *Id.* at 268. Donor tissue can carry communicable diseases, and medical testing cannot identify all infected tissues. *Id.* A medical history can indicate when a particular donor is at high risk for carrying a communicable disease. *Id.* at 283-84. In its regulations for organ and tissue donation, the Food and Drug Administration (FDA) requires both medical testing and the taking

<sup>28.</sup> Ga. Lions Eye Bank v. Lavant, 335 S.E.2d 127, 128 (Ga. 1985).

<sup>29.</sup> State v. Powell, 497 So. 2d 1188, 1191 (Fla. 1986).

<sup>30.</sup> Emile J. Farge et al., *The Impact of State Legislation on Eye Banking*, 112 ARCHIVES OPHTHALMOLOGY 180, 181 (1994).

<sup>31.</sup> Goodwin, *supra* note 9, at 277.

<sup>32.</sup> Data do not appear to be available on the number of organs that have been retrieved, and there have been only occasional reports. The court in Jacobsen v. Marin General Hospital decided a lawsuit by a family that sued over the removal of a decedent's heart, liver, kidney, and pancreas by the coroner in Marin County, California, without the family's permission. 192 F.3d 881, 884 (9th Cir. 1999). The Marin County coroner reports that there have not been any times since the Jacobsen case in which a decedent's organs were removed under the Marin County coroner's presumed consent authority. Telephone Interview with Kenneth Holmes, Marin County, Cal. Coroner (June 16, 2008); see also Jennifer Rutherford-McClure, To Donate or Not to Donate Your Organs: Texas Can Decide for You When You Cannot Decide for Yourself, 6 TEX. WESLEYAN L. REV. 241, 260-61 (2000) (describing the removal of five organs from a person in Fort Worth, Texas who was unidentified at the time of death but later was identified through fingerprint matching); Prerna Mona Khanna, Scarcity of Organs for Transplant Sparks a Move to Legalize Financial Incentives, WALL ST. J., Sept. 8, 1992, at B1 (reporting that coroners in Texas exercised their authority only twice in the first year after the state enacted its presumed consent statute).

of the public have objected to presumed consent, too, and sued after discovering that corneas or organs were taken from their family members without consent.

Nevertheless, courts at first staunchly defended the laws. In three leading cases involving cornea removal statutes, the courts rejected the challenges by family members. The Michigan Court of Appeals upheld that state's cornea removal statute in 1984, finding no constitutional rights at stake.<sup>34</sup> One year later, the Georgia Supreme Court quickly dismissed the possibility that any constitutional rights were being violated, and observed further that there is no more important power for the state than to protect the public health.<sup>35</sup> Accordingly, wrote the court, the presumed consent statute "must be submitted to by individuals for the good of the public."<sup>36</sup> Similarly, the Florida Supreme Court upheld its state's presumed consent statute in 1986, finding no constitutional rights at stake and great benefit from the statute for the citizens of Florida.<sup>37</sup>

In view of the evidence of effectiveness and the receptivity of the courts, the drafters of the UAGA gave their blessing to presumed consent in 1987, though with one important qualification.<sup>38</sup> While many presumed consent statutes permitted retrieval of corneas, pituitary glands, or organs as long as the coroner or medical examiner was simply unaware of objections to donation, the 1987 UAGA required the coroner or other official to make a "reasonable effort" to review the dead person's medical records and speak to family members before implementing presumed consent.<sup>39</sup> Some states followed the 1987 UAGA and included the reasonable effort language while others did not.<sup>40</sup>

Other differences emerged among the states. Some permitted retrieval of any organ or tissue; others restricted retrieval to corneas and/or pituitary glands (even though pituitary gland tissue has not been used for therapeutic purposes since 1985).<sup>41</sup> Some states

of a medical history, but waives the requirement of a medical history when corneas are retrieved from cadavers under state presumed consent statutes. 21 C.F.R. § 1270.21 (2008).

<sup>34.</sup> Tillman v. Detroit Receiving Hosp., 360 N.W.2d 275, 277 (Mich. Ct. App. 1984).

<sup>35.</sup> Ga. Lions Eye Bank v. Lavant, 335 S.E.2d 127, 128-29 (Ga. 1985).

<sup>36.</sup> Id. at 129 (quoting Abel v. State, 13 S.E.2d 507, 511 (Ga. 1941)).

<sup>37.</sup> State v. Powell, 497 So. 2d 1188, 1190-94 (Fla. 1986).

<sup>38.</sup> UNIF. ANATOMICAL GIFT ACT § 4 cmt. (1987).

<sup>39.</sup> *Id.* § 4(a)(2).

<sup>40.</sup> Compare IND. CODE § 36-2-14-19(d)(4)(A) (2008) (requiring a reasonable effort to contact next of kin within six hours of the person's death), with FLA. STAT. § 765.5185 (2005) (permitting cornea removal if the medical examiner is unaware of an objection).

<sup>41.</sup> Compare MINN. STAT. ANN. § 525.9213 (West 2002) (authorizing removal of all organs), repealed by Darlene Luther Revised Uniform Anatomical Gift Act, 2007 Minn.

permitted retrieval of organs or tissues from any decedent under the custody of a coroner or medical examiner; others permitted retrieval only if an autopsy was being performed.<sup>42</sup>

By 1990, presumed consent reached its peak in the United States. Most states had passed statutes and courts were in agreement on the constitutionality of the provisions.

#### II. THE UNRAVELING OF PRESUMED CONSENT IN THE UNITED STATES

The legal tide against presumed consent began to turn in 1991, when the U.S. Court of Appeals for the Sixth Circuit expressed concerns about taking corneas from cadavers without family members having some opportunity to be heard on the matter.<sup>43</sup> In Brotherton v. Cleveland, Deborah Brotherton sued when she found out from an autopsy report that her husband's corneas had been removed.44 Steven Brotherton died by suicide and therefore came under the custody of the Hamilton County, Ohio coroner, Dr. Frank Cleveland.<sup>45</sup> Ohio's presumed consent statute was typical—coroners were allowed to retrieve corneas for transplantation as long as they were unaware "of an[y] objection by the decedent, the decedent's spouse, or, if there is no spouse, the next of kin, the guardian, or the person authorized to dispose of the body."46 As it happened, Deborah Brotherton had refused consent to the taking of her husband's corneas, and her objection was documented in his medical record.<sup>47</sup> However, the Hamilton County coroner's office had adopted a policy "not to obtain a next of kin's consent or to inspect the medical records or hospital documents before removing corneas."48 Indeed, when personnel at the local eye bank started asking about the existence of objections to removals, Dr. Cleveland instructed his staff to withhold information about next of kin.49

Laws ch. 120,  $\S$  26 (codified at MINN. STAT.  $\S$  525A.01-25 (2008)), with N.Y. PUB. HEALTH  $\S$  4222 (McKinney 2008) (authorizing removal of corneas and pituitary glands).

<sup>42.</sup> Compare HAW. REV. STAT. ANN. § 327-4 (LexisNexis 2007) (not requiring autopsy), repealed by 2008 Haw. Sess. Laws ch. 122, § 54 (codified at HAW. REV. STAT. § 327-4 (2008)), with GA. CODE ANN. § 31-23-6(b) (2006) (requiring that an autopsy be performed), repealed by 2008 Ga. Laws 545 § 3 (codified at GA. CODE ANN. § 44-5-140 to -159.4 (2008)).

<sup>43.</sup> Brotherton v. Cleveland, 923 F.2d 477, 482 (6th Cir. 1991).

<sup>44.</sup> Id. at 478.

<sup>45.</sup> Id.

<sup>46.</sup> Id.

<sup>47.</sup> Id.

<sup>48.</sup> Id.

<sup>49.</sup> Brotherton v. Cleveland, 173 F.3d 552, 556 (6th Cir. 1999). The record does not indicate that Dr. Cleveland was driven by a profit motive or other secondary gain. *Id.* Also, a lawyer for the plaintiffs, Stephen A. Bailey, was not aware of any such motive. Telephone Interview with Stephen A. Bailey, Founding Partner, Martin & Bailey

In contrast to the state courts that rejected constitutional claims, the Sixth Circuit recognized a Fourteenth Amendment procedural due process right for family members.<sup>50</sup> The court hinted that actual consent might be required before corneas could be taken, noting that family members have (limited) property rights in a dead person's body under state law and that prior United States Supreme Court case law required a formal hearing before property rights could be infringed under an official government policy like the one in Brotherton.<sup>51</sup> In the end, the court did not decide exactly what level of process was due to Ms. Brotherton, holding only that some process was due to her before the corneas could be taken.52 One could read Brotherton in one of several ways: as requiring only that coroners (and medical examiners) peruse the medical record to make sure they find any documented objections, as requiring coroners to follow the 1987 UAGA and make reasonable efforts to speak to next of kin, or as requiring that coroners actually obtain the next of kin's consent (since a formal hearing would give next of kin the opportunity to either consent or object).

The Ninth Circuit followed the lead of the Sixth Circuit when it faced a similar case to *Brotherton*, *Newman v. Sathyavaglswaran.*<sup>53</sup> *Newman* arose out of rather seamy practices at the Los Angeles County coroner's office.<sup>54</sup> According to an exposé in the *Los Angeles Times*, the L.A. coroner studiously avoided any efforts to speak with family members about taking corneas from dead persons, so no objections could be identified, and there was a strong profit motive for the practice. The coroner's office sold the corneas to a for-profit tissue bank, receiving about \$250,000 a year.<sup>55</sup>

The Newman court's opinion reads much like that of the Brotherton court. After reviewing the history of property rights in cadavers, the court cited the Brotherton court's analysis and stated its agreement that family members may claim property rights in the body of a deceased person.<sup>56</sup> The Newman court then concluded with essentially the same Fourteenth Amendment procedural due process analysis as did the Brotherton court. It cited the U.S. Supreme Court's opinions in which the Court required a formal hearing before property rights could be infringed by the state when the state acted

<sup>(</sup>June 4, 2008).

<sup>50.</sup> Brotherton, 923 F.2d at 481-82.

<sup>51.</sup> *Id*.

<sup>52.</sup> Id.

<sup>53. 287</sup> F.3d 786 (9th Cir. 2002).

<sup>54.</sup> Ralph Frammolino, Harvest of Corneas at Morgue Questioned, L.A. TIMES, Nov.

<sup>2, 1997,</sup> at A1.

<sup>55.</sup> Id.

<sup>56.</sup> Newman, 287 F.3d at 795-98.

under official government policy, but declined to decide exactly what process is due before corneas can be retrieved by coroners or other public officials.<sup>57</sup>

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Although the *Brotherton* and *Newman* courts did not decide what process is due before corneas can be taken from a cadaver for transplantation, their suggestions of a hearing before retrieval raised serious questions about the validity of the presumed consent statutes. In 2006, the drafters of the 2006 UAGA eliminated the provision for presumed consent, citing the *Brotherton* case and observing that the change was made in light of "lawsuits in which [the coroner's] [medical examiner's] actions were held to violate the property rights of surviving family members."<sup>58</sup> In 2007 and 2008, thirty-three states and the District of Columbia enacted the 2006 UAGA, with most of them eliminating presumed consent entirely and only a few retaining it, primarily just for corneas.<sup>59</sup>

In sum, within fifteen years of the *Brotherton* decision, a consensus began to develop that presumed consent should be abandoned. Indeed, in the same year as the issuance of the 2006

<sup>57.</sup> Id. at 799-800.

<sup>58.</sup> REV. UNIF. ANATOMICAL GIFT ACT, Summary of the Changes in the Revised Act (2006) (alterations in original). Professor Michelle Goodwin participated in the discussions leading to the 2006 UAGA. She reports that she initiated the reconsideration of the presumed consent provisions and encouraged their removal over the objections of the representative for the tissue bank industry. Interview with Michele B. Goodwin, Everett Fraser Professor of Law, University of Minnesota, in San Diego, Cal. (Jan. 9, 2009).

Interestingly, representatives of the Eye Bank Association of America did not oppose the elimination of presumed consent by the drafters of the 2006 UAGA. While the Association would have preferred to retain presumed consent as an option for obtaining corneas or other eye tissue, regulations of the FDA require tissue banks to try to obtain a medical history of the decedent as part of the screening process for tissue donation. 21 C.F.R. §§ 1270.21(h), 1271.50, 1271.75 (2008) (requiring donor screening, including review of medical records, which in turn includes a medical interview). Medical testing can pick up most infected tissues, but not all of them. Many experts believe that medical and social histories are important for identifying potential donors who have a high risk of carrying a communicable disease and are therefore not qualified to be tissue donors. For example, a social history can help identify people who have engaged in injection drug use and therefore are have an elevated risk of HIV infection. The most likely providers of the medical and social history are family members. But other experts observe that family members often can add little relevant information beyond what is already included in the medical record. Although the FDA regulations allow the tissue bank to obtain the history from the decedent's primary treating physician, and the tissue bank is only required to try to obtain the medical history, the regulations have eliminated presumed consent to cornea donation for the most part. Eye banks generally will not use corneas unless they can obtain a medical history from a family member-and once they reach a family member for the history, they then can ask for consent to donation. Telephone Interview with Patricia Aiken-O'Neill, Executive Director, Eye Bank Association of America (May 2008).

<sup>59.</sup> See supra notes 18-21 and accompanying text.

UAGA, an influential panel of the Institute of Medicine reviewed the arguments for and against presumed consent and concluded that states should keep explicit consent requirements for organ donation.<sup>60</sup> This chronology of events raises an important question—why is presumed consent apparently being abandoned in the United States?

## III. REASONS FOR THE ABANDONMENT OF PRESUMED CONSENT TO ORGAN DONATION IN THE UNITED STATES

The desire to abandon presumed consent is not obvious. Indeed, the idea of presumed consent has much to commend it. When people die, their hearts, lungs, livers, and kidneys are no longer useful to them, but the organs can prolong the lives of other people, whose own organs have failed. Why waste precious organs by burying them?<sup>61</sup> If presumed consent would increase the likelihood that a person's organs would be transplanted to someone else after the person's death, then social welfare would be greater. From a utilitarian perspective, the adoption of presumed consent makes considerable sense.<sup>62</sup>

One can adduce powerful deontological arguments as well for presumed consent. There is much appeal to the position that people do not "own" their bodies in the way that they own their homes, cars, or clothing. In this view, bodies are not property to be sold or even given away at the discretion of the individual. Rather, people hold their organs in stewardship for God<sup>63</sup> or for society, and when they have gotten their full benefit from the organs, it is time to pass the organs onto other persons who can continue to benefit.

That said, presumed consent has not been successful in the United States, and for several reasons:

# A. Presumed Consent Did Not Address the Main Reason Why People Do Not Become Organ Donors After Death

Importantly, presumed consent in the United States was premised on faulty assumptions about organ donation decisions. The

<sup>60.</sup> COMM. ON INCREASING RATES OF ORGAN DONATION, supra note 7, at 227.

<sup>61.</sup> Dukeminier & Sanders, supra note 8, at 413.

<sup>62.</sup> To be sure, there are some drawbacks to presumed consent even for a utilitarian. If an organ is taken from a person who would not have consented to donation, then family members may suffer substantial psychological discomfort. In addition, a rule of presumed consent might create dissatisfaction with the organ transplant system and make people less willing to donate. More people might then document their objection to being an organ donor.

<sup>63.</sup> *E.g.*, ELLIOTT N. DORFF, MATTERS OF LIFE AND DEATH: A JEWISH APPROACH TO MODERN MEDICAL ETHICS 15 (1998) (describing Jewish belief that bodies are owned by God).

presumed consent statutes were designed to create a default rule in the law that more accurately reflected people's preferences and that overcame obstacles to the vindication of those preferences. Accordingly, for presumed consent laws to have increased the organ supply, the following conditions needed to be true: (a) people generally want to donate their organs, but (b) people's wishes to donate are frustrated because they do not get around to documenting their preferences while alive, and family members often are unreachable to give consent in the short time period in which organs must be removed for transplantation. The Florida Supreme Court's opinion in *State v. Powell* illustrates this thinking:

An affidavit in the record reveals that, before legislation authorized medical examiners in California to remove corneas without the consent of the next of kin, the majority of the families asked by the Los Angeles medical examiner's office responded positively; however, approximately eighty percent of the families could not be located in sufficient time for medical examiners to remove usable corneal tissue from the decedents.<sup>64</sup>

By replacing a requirement for explicit consent with a policy of presumed consent, it was thought that transplant programs would be more likely to obtain organs or tissues that they should be obtaining.

It turns out, however, that organ donation is not frustrated by the inability of transplant personnel to contact family members. Rather, a key reason why organs are not obtained after a person's death is the unwillingness of family members to give consent.<sup>65</sup> Studies have shown that physicians generally are able to talk to family members about donation, but family members often refuse to permit donation.<sup>66</sup> For example, in one careful, national study, researchers found that a family member was unavailable to give consent in less than 3% of cases, but that when family members were asked, they did not give consent 46% of the time.<sup>67</sup> Other researchers also have found a refusal rate of about 50% from families.<sup>68</sup> Because presumed consent as implemented in the United States allowed families to object to donation, it did not address the problem of refusal by family members.

To be sure, presumed consent can increase organ donation rates

<sup>64.</sup> State v. Powell, 497 So. 2d 1188, 1191 (Fla. 1986).

<sup>65.</sup> The failure of people to express their wishes about organ donation while still alive is the other key reason why organs often are not donated after death.

<sup>66.</sup> Sheehy et al., *supra* note 7, at 671.

<sup>67.</sup> Id. (finding also that family members were not asked for consent in 16% of cases).

<sup>68.</sup> See, e.g., Steven L. Gortmaker et al., *Improving the Request Process to Increase Family Consent for Organ Donation*, 8 J. TRANSPLANT COORDINATION 210, 210 (1998) (describing studies in which family refusal rates were 52% and 54%, respectively).

somewhat even if family members are allowed to object.<sup>69</sup> Families may be influenced by the signaling effect of the law's default rule.<sup>70</sup> If society presumes consent instead of presuming non-consent, it suggests to family members that donation is the preferred choice.<sup>71</sup> Some family members may respond to that suggestion by agreeing to donate when they otherwise would have withheld consent.<sup>72</sup>

Presumed consent can increase organ donation rates also by changing the way organ procurement personnel phrase their question to the family.<sup>73</sup> Under an opt-in system, families might be asked whether they know of any reason to think that the decedent would choose to donate.<sup>74</sup> In the absence of any knowledge of the decedent's preferences, the family can easily withhold their consent to organ retrieval.<sup>75</sup> Under an opt-out system, on the other hand, families might be asked whether they know of any reason to think that the decedent would decline donation.<sup>76</sup> The family that is unaware of the decedent's preferences may be inclined to authorize organ retrieval.<sup>77</sup>

Data from countries that employ presumed consent suggest that the shift from an opt-in to an opt-out system can increase organ procurement by as much as 25-30%.<sup>78</sup> However, presumed consent with a family veto would probably have a smaller effect than that in the United States. This is because the per capita rate for organ donation is already higher in the United States than in many countries with presumed consent.<sup>79</sup> In addition, in countries with a presumed consent policy, a family veto reduces the impact of the policy.<sup>80</sup> Still, while presumed consent would not reach most of the organs that are not donated by decedents' families, it could have a

<sup>69.</sup> Kieran Healy, Do Presumed-Consent Laws Raise Organ Procurement Rates?, 55 DEPAUL L. REV. 1017, 1028-29 (2006).

<sup>70.</sup> *Id*.

<sup>71.</sup> Id.

<sup>72.</sup> Id.

<sup>73.</sup> See id. at 1028.

<sup>74.</sup> See id.

<sup>75.</sup> See COMM. ON INCREASING RATES OF ORGAN DONATION, supra note 7, at 212.

<sup>76.</sup> See Healy, supra note 69, at 1028.

<sup>77.</sup> Id.; see also Ori Scott & Eyal Jacobson, Implementing Presumed Consent for Organ Donation in Israel: Public, Religious and Ethical Issues, 9 ISRAELI MED. ASS'N J. 777, 778 (2007).

<sup>78.</sup> Alberto Abadie & Sebastien Gay, *The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study*, 25 J. HEALTH ECON. 599, 610 (2006).

<sup>79.</sup> COMM. ON INCREASING RATES OF ORGAN DONATION, supra note 7, at 213.

<sup>80.</sup> Kai-Lung Hui & Ivan P.L. Png, *Presumed Consent and Cadaveric Organ Donation: Cross-Country Evidence* (National Univ. of Singapore, Working Paper Series), *available at* http://papers.srn.com/sol3/papers.cfm?abstract\_id=1307386.

meaningful impact.<sup>81</sup>

Could presumed consent be implemented in a way that fully addresses the refusals of family members? Organ transplant personnel might identify the reasons for family refusals and develop approaches to family members that would be more likely to elicit their consent. But such approaches could be implemented under a policy of explicit consent, and therefore presumed consent is unnecessary for their success. Alternatively, the United States could adopt a policy of presumed consent without giving families the option of withholding consent. Under this stronger form of presumed consent, consent to organ donation would be assumed unless the decedent objected to donation.

There is good reason to deny family members the option to withhold consent to organ retrieval. Although the law gives decisionmaking authority to the family to carry out the decedent's wishes, family members often do not accurately reflect a dead person's preferences.<sup>82</sup> A person may have wanted to donate organs after death, but family members might refuse consent nevertheless. Indeed, many family members substitute their own preferences for those of the decedent.<sup>83</sup> For example, while family members generally indicate that they base their refusals on the wishes of the decedent,<sup>84</sup> they also often give reasons for their refusals that seem to reflect their own interests. Many family members report that they "had been through enough and therefore could not tolerate the organ donation process," or that they "were concerned that donation would disfigure the body and/or preclude an open-casket funeral."<sup>85</sup>

More importantly, families frequently block organ donation even when a person filled out an organ donor card while alive—and the

<sup>81.</sup> If half of usable organs are retrieved from decedents currently, *see supra* text accompanying note 7, organ procurement personnel would need to increase organ retrieval rates by 100% to maximize the organ supply. Presumed consent, then, might address as much as 25-30% of the lost opportunity.

<sup>82.</sup> See infra note 86 and accompanying text.

<sup>83.</sup> As case law recognizes, family members have their own rights at stake with respect to a decedent's body. Newman v. Sathyavaglswaran, 287 F.3d 786, 796-97 (9th Cir. 2002); Brotherton v. Cleveland, 923 F.2d 477, 482 (6th Cir. 1991). Nevertheless, individuals' rights to determine the disposition of their own organs after death trump the rights of family members to decide on the disposition of decedents' organs. REV. UNIF. ANATOMICAL GIFT ACT § 8(a) (2006).

<sup>84.</sup> When family members explain their reasons for refusing consent, fidelity to the decedent's wishes is the most common reason given. 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) (reporting that 51% of families stated that their refusal reflected their understanding of the decedent's wishes).

<sup>85.</sup> Id.

override rate can be quite high.<sup>86</sup> In Indiana in 2000, family members overrode a decedent's choice to donate in 74 out of 184 cases involving eligible donors who had indicated their wishes on their drivers' licenses.<sup>87</sup> That 40% override rate led the legislature to modify the state's uniform anatomical gift act to make it clear that the decedent's wishes take priority over those of family members.<sup>88</sup>

While presumed consent in the United States did not deal with the possibility of families substituting their own preferences for those of the decedent, one could prevent inappropriate family decisions by implementing the stronger form of presumed consent that allows objections only from the decedent while alive.<sup>89</sup>

This policy option raises two questions: Do people generally want their organs taken after their deaths? If so, would it work to implement a presumed consent system that denies family members any opportunity to object to donation (that is, a stronger version of presumed consent)? As discussed below, one can mount a good, though not decisive, argument that people generally want to be organ donors after death and that presumed consent would vindicate patient autonomy. As to bypassing families, however, the experience in the United States with presumed consent indicates that it has not worked to take organs without family consultation. Excluding families from participation has too greatly reinforced concerns that the organ transplant system would abuse its presumed consent authority.

88. Id.; see also Dave Wendler & Neal Dickert, The Consent Process for Cadaveric Organ Procurement: How Does It Work? How Can It Be Improved?, 285 JAMA 329, 329 (2001) (finding that organ procurement organizations are as likely to follow the family's wishes as to follow the decedent's wishes). Other studies have found lower rates of family override. See, e.g., J.R. Rodrigue et al., Organ Donation Decision: Comparison of Donor and Nondonor Families, 6 AM. J. TRANSPLANTATION 190, 196 (2006) (finding 16.1% override rate in a study of organ donation decisions in a southeastern state).

In response to this problem, states have passed provisions explicitly prohibiting families from overriding a decedent's expressed desire for posthumous donation. IND. CODE ANN. §29-2-16.1-7(a) (LexisNexis 2008) (original version at IND. CODE ANN. § 29-2-16-2.5 (West 2001)); OHIO REV. CODE ANN. § 2108.78 (LexisNexis 2007). The 2006 UAGA recommends a provision to preclude family overrides. REV. UNIF. ANATOMICAL GIFT ACT § 8(a) (2006).

<sup>86.</sup> Jennifer Wagner, Organ Donors Get Final Say Under Law, INDIANAPOLIS STAR, May 7, 2001, at 1A.

<sup>87.</sup> Id.

<sup>89.</sup> Another alternative would be to allow family decision making only when it is clear that the family is acting in accordance with the decedent's wishes. However, it would be difficult to distinguish between faithful and unfaithful families. And if there were clear evidence about the decedent's wishes, it would not be necessary to give decision-making authority to the family. Physicians could simply implement the decedent's clear wishes.

### B. A Stronger Version of Presumed Consent Probably Would Not Work

Consideration of a version of presumed consent that excludes family involvement raises important questions about individual autonomy. If families could not object to organ donation on behalf of the decedent, many more organs would be removed from dead persons. But some of those organs would be taken from decedents who did not want their organs taken but failed to express their objections before their deaths. This has led critics of presumed consent to object on grounds that it would violate principles of autonomy.<sup>90</sup> Our society recognizes the right of persons to accept or reject invasions of their bodies, and that right includes the power to decide whether or not to donate organs. Under a strong presumed consent system, many people would have their organs taken even though they would not have wanted them taken.

It turns out that the argument from autonomy is more complicated than suggested by some critics of presumed consent. A requirement for actual consent can violate autonomy just as easily as can a policy of presumed consent.<sup>91</sup> Under the current policy of actual consent, many people do not become organ donors after death, even though that would be their choice, because they did not express their wishes to donate organs while alive, or because family members override their wishes after their deaths.<sup>92</sup>

If autonomy might be violated with either actual consent or presumed consent, how do we balance the two risks of error? Should we be more worried about the loss of autonomy under presumed consent or the loss of autonomy under actual consent?

# 1. Presumed Consent Might Better Protect Patient Autonomy Than Does Actual Consent

Public views can help us decide whether presumed or actual consent better serves the interests of patient autonomy. How, then, do people feel about presumed consent versus actual consent to organ donation? Polling data sends a mixed message. In a 2005 national survey, 85.9% of the public thought that presumed consent would

<sup>90.</sup> Charles A. Erin & John Harris, *Presumed Consent or Contracting Out*, 25 J. MED. ETHICS 365, 365 (1999).

<sup>91.</sup> See Marie-Andrée Jacob, Another Look at the Presumed-Versus-Informed Consent Dichotomy in Postmortem Organ Procurement, 20 BIOETHICS 293, 294 (2006).

<sup>92.</sup> Although the 2006 UAGA and many states' laws deny family members the authority to override the decedent's wishes, *see supra* note 68, transplant surgeons may be reluctant to retrieve organs in the face of familial opposition. Moreover, many people might express their willingness to donate to family members without documenting their wishes with organ donor cards or on their driver's licenses, so doctors would not know that the family is overriding the decedent's wishes.

increase the organ supply, but only 43.2% supported a system of presumed consent.<sup>93</sup> On the other hand, only 31.3% said they would opt out of a presumed consent system.<sup>94</sup>

There may be better ways to measure people's actual preferences. As James Muyskens has argued, we should consider the question of consent to posthumous organ donation as a question of "health insurance" and ask what a rational person would be willing to "pay" in order to have the health care needed in the event of organ failure.<sup>95</sup> From that perspective, he observes, people generally would be willing to relinquish their right to be buried intact in order to have a decent chance of receiving an organ transplant at a time of need.<sup>96</sup> Very likely, people would choose the greater opportunity to live longer over the greater opportunity to retain organs after death.<sup>97</sup>

One could come to the same conclusion by asking which policy will have the smaller risk of error. Under current policies of actual consent, how many people do not become organ donors despite their desire to donate (erroneous non-donations)? On the other hand, if policies of presumed consent were adopted, how many people would become organ donors despite their opposition to donating (erroneous donations)? We could choose the policy that maximizes the number of people whose wishes are fulfilled.

Under this approach, it appears that presumed consent is the better policy.<sup>98</sup> Public opinion surveys consistently find that a majority of people say they want to have their organs used for transplantation after death.<sup>99</sup> More than 70% of the public states that they are somewhat or very likely to donate,<sup>100</sup> and about 53.2% of people have documented their willingness to donate.<sup>101</sup> It makes sense to base the law's "default" rule according to the majority's

<sup>93.</sup> THE GALLUP ORG., NATIONAL SURVEY OF ORGAN AND TISSUE DONATION ATTITUDES AND BEHAVIORS 21 (2005), ftp://ftp.hrsa.gov/organdonor/survey2005.pdf.

<sup>94.</sup> Id. In a survey of persons who had been asked about donating a deceased family member's organs, only about one-fourth agreed or strongly agreed that presumed consent should be adopted. James R. Rodrigue et al., Attitudes Toward Financial Incentives, Donor Authorization, and Presumed Consent Among Next-of-Kin Who Consented vs. Refused Organ Donation, 81 TRANSPLANTATION 1249, 1253 tbl.4 (2006).

<sup>95.</sup> Muyskens, supra note 8, at 97.

<sup>96.</sup> Id.

<sup>97.</sup> Id. at 97-98.

<sup>98.</sup> See Carl Cohen, The Case for Presumed Consent to Transplant Human Organs After Death, 24 TRANSPLANTATION PROCEEDINGS 2168, 2169 (1992); Gill, supra note 8, at 44-51.

<sup>99.</sup> THE GALLUP ORG., *supra* note 93, at 6.

 $<sup>100. \</sup> See \ id.$  (finding that 78.2% of the public is very likely or somewhat likely to donate organs after death).

<sup>101.</sup> See id. at 10.

preference. That is, if 70% of people want to donate organs and only 30% do not want to donate, the law should assume that people want to donate, thereby satisfying 70% rather than 30% of the population.

Of course, it is more complicated than that. People can opt out of default rules. Under our current system, we assume people do not want to donate organs after death, but they or their families can overcome this presumption by giving consent to donation (and many in fact do so). Conversely, in a strong presumed consent system, we would assume that people want to donate their organs after death, but they could overcome such a presumption by expressing their opposition to donation. And so we have to ask different questions: Under a policy of actual consent, how many people fail to express their wishes and therefore lose the opportunity to become organ donors? Under a policy of presumed consent, how many people would fail to express their wishes and therefore become unwilling organ donors?

Even with these questions, presumed consent would seem to result in fewer errors than does a requirement of actual consent. After all, in a presumed consent system, no more than 30% of the public would become unwilling donors by failing to lodge their objections to donation (since less than 30% of the public classifies itself as "not very/not at all likely" to donate).<sup>102</sup> In contrast, under the current system, more than 70% of the public could fail to express their desire for donation and lose their opportunity to become donors.<sup>103</sup> Or, someone while alive might express willingness to donate organs after death, but family members might withhold consent to donation. At the time of a loved one's death, when grief is overwhelming, people may be offended by a request for organ donation, or they may feel that granting permission for donation would violate or demean the dead person.<sup>104</sup>

Moreover, we might expect those who oppose donation to be more scrupulous than those who desire donation about expressing their wishes. Opposition to donation likely will reflect a deeply held moral view, and just as Jehovah's Witnesses are careful to express their opposition to blood transfusions, so might people objecting to organ donation be careful to express their views under a presumed consent system.<sup>105</sup> And as Linda Fentiman suggests, it would be possible to

<sup>102.</sup> See id. at 6.

<sup>103.</sup> See *id*. (applying the same rationale that the 78.2% of those polled by Gallup classify themselves as "very likely" or "somewhat likely" to donate).

<sup>104.</sup> Muyskens, *supra* note 8, at 96. The likelihood that a family member would override a decedent's wishes to donate may be as high as 40%. *See* Wagner, *supra* note 86, at 1A.

<sup>105.</sup> Gill, *supra* note 8, at 41. Opponents of presumed consent observe that people typically are unaware of the law regarding organ donation, and under a presumed

provide ample opportunity for people to document their objection to organ donation.<sup>106</sup> She proposes a national, electronic registry and a system in which people could register their objections "when obtaining or renewing a driver's license; on filing an income tax return; when applying for welfare[,] disability or other governmental benefits; [and] on every visit to a hospital or doctor's office ...."<sup>107</sup>

In short, it may well be the case that a regime of strong presumed consent would more likely ensure that society carries out a person's wishes about organ donation after death.

## 2. Actual Consent Might Better Protect Autonomy Than Would Presumed Consent

There also is evidence supporting the view that there are fewer erroneous non-donations under a policy of actual consent than there would be erroneous donations under a policy of presumed consent. The argument for presumed consent rests in large part on the survey data showing a strong majority of people who say they would want their organs taken after death.<sup>108</sup> But while a large majority of the public reports a preference for organ retrieval, barely more than half of the public actually document a desire to be an organ donor after death.<sup>109</sup> How then do we interpret this discrepancy? Is it that the great majority of persons do want to donate, but many simply fail to take the necessary steps to document their preferences? Or is it that almost half of persons really do not want to be organ donors, but many of them give the socially preferred response in public opinion surveys? If barely half of the public actually wants to be an organ donor, then a policy of presumed consent could easily lead to more erroneous donations than the number of erroneous non-donations that occur under our policy of actual consent.

The possibility that people really do not want to be organ donors is particularly important with minorities. Public opinion surveys find less support among the poor and minorities than among the well-to-

108. See supra Part III.B.1.

consent system, many people will fail to lodge their objection to donation out of ignorance of the law. However, the same problem exists with a policy of actual consent. Many people who want to donate their organs fail to express their wishes currently. *Id.* at 41-42.

<sup>106.</sup> Linda C. Fentiman, Organ Donation as National Service: A Proposed Federal Organ Donation Law, 27 SUFFOLK U. L. REV. 1593, 1600 (1994).

<sup>107.</sup> *Id.* (proposing also that objections could be documented when the person is asked to consider organ donation or when executing a living will or other advance directive). It would be critical to include something like the Fentiman proposal if presumed consent were to be adopted, along with assurances that people would be made aware of the option to express their objections to organ donation when the opportunities for opting out arise.

<sup>109.</sup> THE GALLUP ORG., *supra* note 93, at 10.

do or whites.<sup>110</sup> While 60.5% of whites have granted permission for organ donation on their drivers' licenses, only 39.3% of Latinos, and 31.2% of blacks have done so.<sup>111</sup> Vulnerable populations are not only less likely to support organ donation; they also would be less likely to realize that presumed consent statutes exist and that they would need to lodge their objections to organ donation. Without a reliable method of opting out of presumed consent, presumed consent could easily operate to the particular disadvantage of vulnerable populations. Indeed, Marie-Andrée Jacob has argued that the possibility of unfairness to vulnerable populations should push us toward actual consent.<sup>112</sup> Analogizing to contract law, which places on the more powerful party the burden of contracting out of default rules, she suggests that default rules for posthumous organ donation place the burden on doctors to overcome the rules.<sup>113</sup> In other words, the burden should remain on physicians to obtain consent to organ donation rather than placing the burden on individuals to express their objection to donation.114

There are other considerations to take into account. While one policy may reflect the preferences of the majority, the minority may have more at stake in the decision whether to take organs without actual consent. In other words, the harm from an erroneous donation under presumed consent may be greater than the harm from an erroneous non-donation under actual consent. And often in balancing risks of error, we compare not only the number of people that might be wronged, but also the magnitudes of the risks of error. For example, the criminal law requires prosecutors to prove guilt beyond a reasonable doubt<sup>115</sup> because of the view that it is much worse to convict an innocent person than to acquit a guilty person<sup>116</sup> (or better to let ten guilty people go free than imprison one innocent person).

Similarly, on the question of withdrawing life-sustaining treatment from persons who no longer can speak for themselves, many states require the provision of treatment unless there is clear and convincing evidence that the patient would not want the treatment.<sup>117</sup> As with criminal prosecutions, the states erect a high

<sup>110.</sup> See id. at 6.

<sup>111.</sup> Id. at 11; see also Laura A. Siminoff et al., Racial Disparities in Preferences and Perceptions Regarding Organ Donation, 21 J. GEN. INTERNAL MED. 995, 997 (2006) (finding in a survey of Ohioans that 64.9% of whites but only 39.1% of blacks had signed an organ donor card or other document).

<sup>112.</sup> Jacob, *supra* note 91, at 299-300.

<sup>113.</sup> *Id*.

<sup>114.</sup> *Id*.

<sup>115.</sup> WAYNE R. LAFAVE, CRIMINAL LAW § 1.8(g) (4th ed. 2003).

<sup>116.</sup> *Id.* § 1.4.

<sup>117.</sup> See ORENTLICHER ET AL., supra note 5, at 285-86. Other states allow the withdrawal of life-sustaining treatment when family members request withdrawal, or

procedural threshold when it comes to the withdrawal of care from an incapacitated person. These states could ask simply whether it is more likely than not that a person would refuse life-sustaining treatment, but they instead weight their policies in favor of providing the treatment. Even though such policies mean that many people receive undesired treatment, it reduces the possibility that someone will be denied desired treatment. For these states, it is better that several people be kept alive too long than one person die too soon.

How does this approach play out with presumed consent to organ donation? Is it worse to take organs when the patient would not have wanted them taken, or is it worse to leave organs when the patient would have wanted them taken? At first glance, there is no harm or benefit either way.<sup>118</sup> Taking or leaving organs has no effect on the welfare of a dead person. However, we believe it matters whether we respect the previously expressed wishes of a dead person because of the importance of such respect for people when they are still alive.<sup>119</sup> That is, people want to know that they will be treated after their death as they wish to be treated. Thus, for example, we assure people that they can direct the disposition of their property after they die by writing a will, and we assure people they can direct the disposition of their bodies after they die by expressing a preference for burial or cremation.<sup>120</sup>

There are two important reasons why we might view the harm from an erroneous donation under presumed consent as worse than an erroneous non-donation under actual consent. First, religious beliefs may be more important in decisions not to donate than in decisions to donate.<sup>121</sup> Some people may have strong religious objections to being an organ donor, but other people may not have a strong religious desire to be an organ donor. On the other hand, the religious argument may not be insurmountable. While it is commonly believed that orthodox religious doctrine rejects organ donation, this is not actually the case.<sup>122</sup> Indeed, organ donation is permitted by

when it is in the best interests of the patient to forgo further treatment. Id. at 286-89.

<sup>118.</sup> Veronica English & Ann Sommerville, *Presumed Consent for Transplantation:* A Dead Issue After Alder Hey?, 29 J. MED. ETHICS 147, 150 (2003).

<sup>119.</sup> Gill, *supra* note 8, at 44-45.

<sup>120.</sup> *Id.* at 46. To be sure, we can explain in a number of ways society's recognition of the previously expressed wishes of dead persons. We may do so to avoid psychological injury to the person's surviving family, we may do so to ensure that people are not anxious about what happens to their families or themselves after death, and we may do so to promote socially-desirable behavior. As to the last point, society promotes wealth-creating behavior by allowing people to write wills that leave their accumulated wealth to their children or other people or causes.

<sup>121.</sup> English & Sommerville, supra note 118, at 149.

<sup>122.</sup> Maxwell J. Mehlman, *Presumed Consent to Organ Donation: A Reevaluation*, 1 HEALTH MATRIX 31, 50-53 (1991).

many mainstream religious denominations.<sup>123</sup> Orthodox Judaism, for example, permits organ retrieval after death, as long as physicians can demonstrate that a specific person stands to lose his or her life or an entire physical ability (e.g., the ability to see) without the donation.<sup>124</sup> At the same time, religious doctrine may even impose a duty to donate one's organs.<sup>125</sup> In short, it does not appear that religious considerations should doom presumed consent, but other considerations might.

In particular, it may be the case that people who object to organ donation feel more strongly about their objection, even if not religiously based, than people who desire organ donation feel about their wishes.<sup>126</sup> Under the current system, potential organ donors know that their desire to be an organ donor after death may be unfulfilled. In a presumed consent system, non-donors would know that their objections to organ donation might not be respected. It is very possible that the anxiety from the possibility of unwanted organ donation would be more serious than the anxiety from losing the chance to be an organ donor. People tend to worry more about losing something they have already, and wish to keep, than about not getting something they want.<sup>127</sup>

Indeed, there is good reason to think that the distress to the living from the possibility that their organs might be taken after death is more substantial than the distress from the possibility that organs might not be taken. While there are a number of lawsuits brought by family members when a dead person's organs or tissues have been removed without consent,<sup>128</sup> there are not comparable lawsuits brought by family members when organs have not been removed despite the decedent's or family's wishes for donation.

In sum, one can adduce good arguments from considerations of autonomy to both justify and reject a strong version of presumed consent that excludes family involvement. But even if one concludes that family involvement in the donation decision tends to result in family members overriding individual preferences in favor of donation, the option of excluding families from the donation decision

<sup>123.</sup> Id.

<sup>124.</sup> DORFF, supra note 63, at 226-27.

<sup>125.</sup> Id. at 227-28.

<sup>126.</sup> See Lori B. Andrews, My Body, My Property, 16(5) HASTINGS CENTER REP. 28, 30 (1986).

<sup>127.</sup> Eric J. Johnson & Daniel G. Goldstein, *Defaults and Donation Decisions*, 78 TRANSPLANTATION 1713, 1714 (2004).

<sup>128.</sup> See supra text accompanying notes 34-37, 43-55; see also Jacobsen v. Marin Gen. Hosp., 192 F.3d 881 (9th Cir. 1999) (involving a lawsuit by parents after a man's organs were removed by a coroner). Although a family's lawsuit may reflect its own distress, the point still stands. Families appear to be more distressed when organs are taken without consent than when organs are not taken despite consent.

has not proved feasible in the United States. Indeed, as discussed above, when coroners tried to exclude families from cornea donation decisions, they only provoked a backlash that led to the abandonment of presumed consent by the drafters of the 2006 UAGA.<sup>129</sup> Why this happened is the topic for the next section of this Article.

> 3. Physician Authority to Take Organs Without Consent or Family Involvement Increased Public Concern About the Integrity of the Organ Transplant System

Organ transplantation policy is regularly influenced by the need to maintain public trust in the system of organ procurement and allocation. Given the serious shortage of organs, people worry that transplant personnel will act wrongly in procuring organs or in allocating them.

Employing presumed consent and also excluding families from the donation decision may increase public concerns about the transplant system. Indeed, for centuries, people have worried that the pursuit of medical and scientific interests will lead doctors to engage in misconduct when it comes to securing body parts, and for centuries, there have been dishonest physicians who validated those concerns.

There are two aspects to the concern about unscrupulous behavior by doctors or others. First, coroners or physicians may take organs and other body parts after death against the known wishes of the dead person (or of the decedent's family members). In other words, erroneous donations may occur, not only because mistakes will be made, but also because of intentional misconduct. Second, and more worrisome, coroners or doctors may not wait until death to take the organs—the great need for organs may result in practices that shorten patients' lives. Indeed, even under our current system of actual consent, people worry that doctors may declare death prematurely to free up organs for transplantation.<sup>130</sup> Or they worry that doctors may not treat diseases aggressively enough in order to hasten the availability of organs for transplantation.<sup>131</sup> In one study of families' reasons for refusing to donate the organs of deceased persons, 25% of families cited mistrust of the health care system as a

<sup>129.</sup> See supra text accompanying notes 58-59.

<sup>130.</sup> Siminoff et al., *supra* note 111, at 997-98 (finding that 17% of whites and 32% of blacks in Ohio felt that doctors cannot be trusted to pronounce death correctly when a person is eligible to donate organs); *see also* Gina Kolata, *Controversy Erupts Over Organ Removals*, N.Y. TIMES, Apr. 13, 1997, at A28.

<sup>131.</sup> Siminoff et al., *supra* note 111, at 998 (finding that 26% of whites and 39% of blacks in Ohio said that if doctors know they are organ donors, the doctors would not try to save their lives); *see also* English & Sommerville, *supra* note 118, at 149.

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basis for their refusal.<sup>132</sup>

Transplant professionals place a high priority on reassuring the public and building trust in the organ transplant system. Indeed, in the wake of two recent organ donation controversies, experts emphasized concerns about maintaining public trust. In July 2007, prosecutors filed felony charges against a transplant surgeon in California, alleging that he hastened the death of a patient whose family had agreed to donation.<sup>133</sup> In discussing the charges, an organ donation advocate observed that "we spend an inordinate amount of time telling people [that these kinds of abuses] won't happen."134 In a second controversy in August 2008, transplant surgeons in Colorado provoked a major debate after reporting a practice of retrieving hearts from infants who were declared dead because their hearts had stopped beating for seventy-five seconds.<sup>135</sup> The organs were then transplanted into other infants and the heartbeats restored.136 Critics observed that the first infants were not actually dead when their hearts were removed because the cessation of their heartbeats was not irreversible,<sup>137</sup> and one leading expert predicted that the transplant community would reject the seventy-five-second standard.<sup>138</sup> Dr. James Bernat stated that "there is a primal fear people have of being declared dead wrongly."139 He went on to say that "physicians and transplant enterprises need to be mindful to reassure skeptical people that there will be no instance in which surgeons will procure organs from someone before they are dead."<sup>140</sup> Academic debates over specific organ procurement or allocation policies make the same point-the impact of those policies on public trust plays a critical role in assessing their acceptability.<sup>141</sup>

<sup>132.</sup> Siminoff et al., *supra* note 84, at 972 tbl.2.

<sup>133.</sup> Charles Ornstein & Tracy Weber, *Doctor Charged in Death of Donor*, L.A. TIMES, July 31, 2007, at A1. A jury acquitted the surgeon after his trial. *See Jesse McKinley, Surgeon Cleared of Harming Man to Rush Organ Removal*, N.Y. TIMES, Dec. 19, 2008, at A30.

<sup>134.</sup> Jesse McKinley, *Surgeon Accused of Speeding a Death to Get Organs*, N.Y. TIMES, Feb. 27, 2008, at A1 (quoting David Fleming, Executive Director, Donate Life America).

<sup>135.</sup> See David Armstrong, New Technique to Transplant Hearts in Babies, WALL ST. J., Aug. 14, 2008, at D1; see also Mark M. Boucek et al., Pediatric Heart Transplantation After Declaration of Cardiocirculatory Death, 359 NEW ENG. J. MED. 709 (2008).

<sup>136.</sup> Boucek et al., *supra* note 135, at 709-10.

<sup>137.</sup> Robert M. Veatch, Donating Hearts After Cardiac Death—Reversing the Irreversible, 359 NEW ENG. J. MED. 672, 673 (2008).

<sup>138.</sup> James L. Bernat, *The Boundaries of Organ Donation After Circulatory Death*, 359 NEW ENG. J. MED. 669, 670-71 (2008).

<sup>139.</sup> Armstrong, supra note 135 (quoting Dr. James Bernat).

<sup>140.</sup> *Id*.

<sup>141.</sup> See, e.g., James M. DuBois, Non-Heart-Beating Organ Donation: A Defense of

Under a system of presumed consent that excludes a role for families, the risk that doctors or other professionals will cut corners to obtain organs for transplantation may be much greater than it is under a system of actual consent. With actual consent, there is greater oversight of the organ transplant system—family members have to be much more involved in the process of organ retrieval with actual consent since they are the primary givers of consent to posthumous organ donation. If transplant professionals were able to proceed with organ retrieval without speaking to family members, there would be less of an opportunity for family members to recognize unethical behavior.

Excluding family participation in the organ donation decision may or may not promote unscrupulous practices by transplant professionals. Such a policy would result in more organs becoming available for transplantation, relieving a good deal of the organ shortage. With an increase in available organs, coroners, physicians, and others should feel less pressure to secure organs and therefore be more willing to meet their ethical and legal obligations.

The historical evidence provides support for both possibilities. Grave robbing for medical study and research in the eighteenth and nineteenth centuries largely disappeared when legal reform generated a sufficient supply of cadavers for dissection.<sup>142</sup> On the other hand, there are prominent recent examples of coroners abusing their presumed consent authority when their practices were not adequately monitored. As mentioned above and discussed further below, the recent examples of misconduct under presumed consent played a critical role in leading the drafters of the 2006 UAGA to abandon presumed consent.<sup>143</sup>

# a. Reducing the Risk of Misconduct by Relieving the Shortage of Organs

The possibility that presumed consent would reduce the risk of professional misconduct by alleviating the organ shortage is

the Required Determination of Death, 27 J.L. MED. & ETHICS 126, 132 (1999) (observing that allowing organ procurement from dying patients before death could undermine trust in the medical community); Alvin H. Moss & Mark Siegler, Should Alcoholics Compete Equally for Liver Transplantation?, 265 JAMA 1295, 1297 (1991) (arguing for lower priority for alcoholics in receiving liver transplants to protect public support for the organ transplant system); Robert D. Truog, Brain Death—Too Flawed to Endure, Too Ingrained to Abandon, 35 J.L. MED. & ETHICS 273, 277 (2007) (discussing the debate over implementation of brain death protocols for organ removal).

<sup>142.</sup> Aaron D. Tward & Hugh A. Patterson, From Grave Robbing to Gifting: Cadaver Supply in the United States, 287 JAMA 1183, 1183 (2002).

<sup>143.</sup> See supra text accompanying notes 58-59.

suggested by the Anglo-American experience with grave robbing.<sup>144</sup> In the late 1700s and early 1800s, grave robbing and even murder were serious problems in America and Great Britain, as criminals found a ready market for dead bodies in medical schools that were teaching or conducting research in human anatomy.145 It was during this period that Mary Wollstonecraft Shelley published Frankenstein,<sup>146</sup> which told the story of a scientist, Victor Frankenstein, who created his "monster" out of body parts secured from various morgues and cemeteries. The notorious Burke and Hare homicides in Scotland in the 1820s ultimately brought an end to grave robbing for dead bodies in the United Kingdom and in some of the United States by prompting the passage of legislation permitting the dissection of unclaimed corpses.<sup>147</sup> It took several more decades and other notorious cases before all of the United States passed similar legislation. In 1878, for example, the robbing of U.S. Senator John Scott Harrison's<sup>148</sup> body from his grave led to anatomy laws in Ohio and Indiana. By the beginning of the twentieth century, unclaimed corpses became the general source of bodies for dissection in the United States.149

In short, once medical schools had a reliable supply of cadavers for their teaching and research, doctors no longer looked to the black market for cadavers, and the grave robbing came to an end. If presumed consent greatly increased the supply of organs, then might we also see a diminution in the degree of professional misconduct with respect to organ procurement?

If such a diminution occurred, it would be very important. Unfortunately, the serious shortage of organs has engendered a significant risk of misconduct. Contemporary examples of abuse are not difficult to find. Indeed, in the past few years alone, news media have highlighted a number of problems, including:

• claims that a physician-led, criminal ring in India forcibly took hundreds of kidneys from poor laborers for transplantation,<sup>150</sup>

· the removal of bone from British broadcaster Alistair Cooke's

145. *Id*.

<sup>144.</sup> See Tward & Patterson, supra note 142, at 1183.

<sup>146.</sup> MARY WOLLSTONECRAFT SHELLEY, FRANKENSTEIN, OR, THE MODERN PROMETHEUS: THE 1818 TEXT (James Rieger ed., University of Chicago Press 1982) (1818); *cf.* RUTH RICHARDSON, DEATH, DISSECTION AND THE DESTITUTE xiii (2d ed. 2000) ("[B]odysnatching was rife throughout Mary Shelley's childhood and early adult life.").

<sup>147.</sup> Tward & Patterson, *supra* note 142, at 1183.

<sup>148.</sup> *Id.* Senator Harrison was the son of President William Henry Harrison and the father of President Benjamin Harrison. *Id.* 

<sup>149.</sup> Id.

<sup>150.</sup> Amelia Gentleman, *Kidney Theft Ring Preys on India's Poorest Laborers*, N.Y. TIMES, Jan. 30, 2008, at A3.

body and the taking of body parts from other persons without consent for sale to tissue processing companies,<sup>151</sup> and

• criminal charges against a transplant surgeon in California accused of hastening the death of a dying patient so his organs could be removed for transplantation.  $^{152}$ 

While there is reason to think that a strong version of presumed consent could have a salutary effect on physician conduct, the U.S. experience with presumed consent has in fact reinforced concerns that it would encourage additional misconduct. As discussed in the next section, the possibility that presumed consent would make organ removal practices prone to an even greater risk of abuse than exists currently under actual consent seems to have been realized.

### b. Abuse by Professionals of Their Presumed Consent Authority

For those who worry that transplant professionals will abuse their presumed consent authority, they need look no further than the litigation over presumed consent statutes in the United States. Recall the *Brotherton* case in which an Ohio coroner went out of his way to avoid discovering objections to cornea retrieval from decedents.<sup>153</sup> That case ultimately led to a settlement in which \$5,250,000 was paid to compensate the families harmed by the coroner's policy.<sup>154</sup> Similarly, in *Newman*, the coroner also took extra steps not to discover objections to donations,<sup>155</sup> profiting to the tune of \$250,000 a year.<sup>156</sup> That case was ultimately settled under an agreement of confidentiality,<sup>157</sup> and the California legislature responded to the public outrage by repealing its presumed consent statute.<sup>158</sup> These cases provided validation to people who were concerned that doctors<sup>159</sup> would abuse their authority when they could act without the need for consent; the cases ultimately led the

- 155. Newman v. Sathyavaglswaran, 287 F.3d 786, 788 (9th Cir. 2002).
- 156. Frammolino, *supra* note 54.
- 157. Telephone Interview with Cheryl Orr, Attorney for the Coroner (June 4, 2008).

<sup>151.</sup> Michael Brick, *Alistair Cooke's Bones Were Plundered, His Daughter Says*, N.Y. TIMES, Dec. 23, 2005, at B4. Ultimately, participants in the profiteering racket were convicted for taking Cooke's bones and the tissues of other dead persons without consent. Scott Shifrel, *Victim Lashes Out as Ghoul Gets 18-54 Years*, N.Y. DAILY NEWS, Jun. 28, 2008, at 22.

<sup>152.</sup> McKinley, *supra* note 134. The California medical licensing board also launched a disciplinary action against the surgeon. Rong-Gong Lin II, *Board Targets Doctor's License*, L.A. TIMES, Jun. 6, 2008, at B3.

<sup>153.</sup> Brotherton v. Cleveland, 141 F. Supp. 2d 894, 898 (S.D. Ohio 2001).

<sup>154.</sup> Id. at 901.

<sup>158. 1998</sup> Cal. Adv. Legis. Serv. 887 (West). Interestingly, the legislature only repealed presumed consent for corneas, retaining presumed consent for organs. *Id.* 

<sup>159.</sup> In both cases, the coroners were physicians.

drafters of the 2006 UAGA to drop their support for presumed consent and most states to abandon presumed consent.<sup>160</sup>

The public response to the coroners' actions in *Brotherton* and *Newman* may have reflected not only concerns about coroners ignoring the interests of dead persons and their families; there also appears to have been real concern with the evidence suggesting that presumed consent was implemented in a discriminatory fashion.

## c. Discriminatory Implementation of Presumed Consent

Nearly twenty years ago, in a provocative article about mandatory organ donation, Guido Calabresi observed that legal obligations for people to be organ donors might not be unconstitutional, as long as the laws were applied evenhandedly.<sup>161</sup> As he implied, it might not be any worse for the state to take hearts, livers, or kidneys after a person's death for transplantation than to tax a person's income to fund social services.<sup>162</sup> But even if legal mandates to donate organs might be constitutionally acceptable, they would have to apply to all persons, regardless of their race, sex, religion, etc. If we are going to impose duties to come to the aid of others, Calabresi argued, we must be careful not to impose those duties only on minorities who cannot protect themselves from the majority.<sup>163</sup> If the duties are imposed in a discriminatory way, then they should be struck down by the courts.<sup>164</sup>

How do considerations of fairness apply to presumed consent in the United States? Recall that the presumed consent statutes authorized presumed consent only for persons under the custody of coroners or medical examiners. At first glance, this seems like a reasonable restriction. For those cadavers, coroners and medical examiners already will be performing autopsies. Inasmuch as an autopsy entails a major invasion of the cadaver, taking organs for transplantation seems less offensive than it might otherwise be. In this regard, it is important that states have been more likely to permit retrieval of corneas with presumed consent than to permit retrieval of hearts, livers, and other organs. Corneas are a thin, transparent layer of tissue whose presence or absence cannot be detected by the naked eye. The intrusion from taking a cornea does not compare to the intrusion of an autopsy.<sup>165</sup>

<sup>160.</sup> See supra text accompanying notes 58-59.

<sup>161.</sup> Guido Calabresi, Do We Own Our Bodies?, 1 HEALTH MATRIX 5, 13 (1991).

<sup>162.</sup> Id. at 18.

<sup>163.</sup> Id. at 11-14.

<sup>164.</sup> Id. at 13-14.

<sup>165.</sup> State v. Powell, 497 So. 2d 1188, 1191 (Fla. 1986).

Moreover, while people under the custody of coroners or medical examiners are not representative of the general population, they may be representative of the population of potential organ donors. Data indicate that over half and perhaps two-thirds of potential organ donors are under the custody of coroners or medical examiners,<sup>166</sup> so restricting organ retrieval to such persons may not disfavor minorities.

On closer consideration, concerns about fairness are very serious. While the state statutes cover any person who comes under the custody of a coroner or medical examiner, the population of such persons may be disproportionately poor and minority, at least in major urban centers.<sup>167</sup> Moreover, disparities may exist when coroners or medical examiners decide whether to retrieve organs or tissues from a dead person under their custody. When the *Los Angeles Times* exposed the cornea retrieval practices of the county coroner, the newspaper found that that over 80% of the corneas came from blacks or Latinos.<sup>168</sup> Given the overrepresentation of minorities and poor persons, one has to wonder whether the presumed consent statutes would ever have been passed if they applied equally to wealthy white families as to poor black families.

In sum, the experience in the United States with presumed consent can easily be seen by the public as validation for their fears that physicians will abuse their authority when families are excluded from the organ donation decision. Apparently, physicians will take organs in disregard of people's wishes, and they will do so in a discriminatory fashion.

To be sure, it is important to remember that all of this discussion about abuse is not dispositive, but only suggestive. One could argue that the coroners in *Brotherton* and *Newman* would not have abused their authority if the law had called for presumed consent and excluded families from participation in the donation decision. After all, it was the exclusion of families that constituted the primary abuse by the two coroners.

<sup>166.</sup> J. Keith Pinckard et al., National Association of Medical Examiners' Position Paper on the Medical Examiner Release of Organs and Tissues for Transplantation, 28 AM. J. FORENSIC MED. PATHOLOGY 202, 205 (2007) (stating that 62.1% of potential donors are under custody of medical examiners and/or coroners); Teresa J. Shafer et al., Vital Role of Medical Examiners and Coroners in Organ Transplantation, 4 AM. J. TRANSPLANTATION 160, 162 (2004) (indicating that 56% of donors were under custody of medical examiners and/or coroners). Over time, the jurisdiction of coroners and medical examiners has expanded considerably; it now includes persons who die when unattended by a physician. See, e.g., FLA. STAT. § 406.1(1)(a)(5) (2008); N.C. GEN. STAT. § 130A-383(a) (2008).

<sup>167.</sup> Goodwin, supra note 9, at 285-86.

<sup>168.</sup> Frammolino, *supra* note 54.

But whether or not a different approach to presumed consent would have played out differently, the drafters of the 2006 UAGA and state legislatures have decided to abandon presumed consent, and it is difficult to envision a revival of presumed consent in a stronger version in the near future.

Indeed, even in other countries which have had a better experience with presumed consent than in the United States, there is a tremendous reluctance to proceed without family involvement.

# C. Presumed Consent Has Not Been More Successful in Other Countries

Many scholars cite the experience of other countries, particularly those in Western Europe, as support for presumed consent. However, close examination indicates that the experience elsewhere also demonstrates the infeasibility of implementing presumed consent without the involvement of family members.

Indeed, when Brazil tried to implement a presumed consent regime in which objections could be lodged only by individuals for themselves, it provoked a backlash among the public, leading many people to refuse donation.<sup>169</sup> The public reaction led to the repeal of the presumed consent law.<sup>170</sup>

Studies have considered the impact of presumed consent laws in other countries, and researchers disagree about the effect of the laws. Some studies suggest that presumed consent laws do not increase the likelihood of organ retrieval for transplantation. In one ten-country comparison, for example, the authors found that the higher rates of organ donation in presumed consent countries could be explained by medical considerations rather than the effects of the presumed consent laws.<sup>171</sup> Other studies suggest that presumed consent laws do in fact result in higher rates of organ retrieval. In a twenty-twocountry comparison, researchers concluded that presumed consent statutes may increase organ transplantation by 25-30%.<sup>172</sup> Similarly,

<sup>169.</sup> Claudio Csillag, Brazil Abolishes "Presumed Consent" in Organ Donation, 352 LANCET 1367, 1367 (1998).

<sup>170.</sup> Id.; see also Everton Bailey, Comment, Should the State Have Rights to Your Organs? Dissecting Brazil's Mandatory Organ Donation Law, 30 U. MIAMI INTER-AM. L. REV. 707, 708-09 (1999).

<sup>171.</sup> Remco Coppen et al., *Opting Out Systems: No Guarantee for Higher Donation Rates*, 18 TRANSPLANTATION INT'L 1275, 1277-78 (2005) (finding that higher donation rates in presumed consent countries can be explained by higher rates of death from motor vehicle accidents or other causes that likely will leave the decedent in a condition suitable for organ donation).

<sup>172.</sup> Alberto Abadie & Sebastien Gay, *The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross-Country Study*, 25 J. HEALTH ECON. 599, 610 (2006); *see also* Eric J. Johnson & Daniel Goldstein, *Do Defaults Save Lives?*, 302 SCIENCE 1338, 1339 (2003) (finding higher donation rates in presumed consent

after Singapore adopted presumed consent, liver transplants increased by 35%.<sup>173</sup>

Part of the uncertainty about the impact of presumed consent laws reflects an important gap between law and practice—doctors in presumed consent countries typically seek family consent even though the family's consent is not required.<sup>174</sup> In addition, presumed consent countries with high retrieval rates employ other measures to increase the organ supply, and those other measures may be responsible for the higher rates.<sup>175</sup> Spain's high rate of organ donation, for example, appears to reflect a well-developed organ transplant system overseen by a national network of speciallytrained and highly-motivated transplant physicians.<sup>176</sup> In fact, while Spain has the highest donor rate ever reached by a country and its law calls for presumed consent, doctors always seek family consent, and they always respect the wishes of the next of kin.<sup>177</sup>

In short, the evidence from other countries confirms the experience in the United States that it is difficult, and perhaps impossible, to implement presumed consent without family involvement.

#### CONCLUSION

Although presumed consent has fallen out of favor in the United States, this country's experience with that approach leaves some important lessons.

First, to maximize the number of people who become organ donors after death, greater efforts must be made to increase the

countries than in actual consent countries).

<sup>173.</sup> How-Cheng Low et al., Impact of New Legislation on Presumed Consent on Organ Donation on Liver Transplant in Singapore: A Preliminary Analysis, 82 TRANSPLANTATION 1234, 1236 (2006).

<sup>174.</sup> Austria is the one European country where transplant physicians generally do not obtain family consent. Janssen & Gevers, *supra* note 1, at 580; Mehlman, *supra* note 122, at 40-42. But even there, doctors will respect a family's objection. Gerhard Aigner, *An Overview of Legal Aspects in Organ Transplantation—What Are the Family Rights*?, 9 ANNALS TRANSPLANTATION 11, 14 (2004). Even if physicians seek family consent in presumed consent countries, the existence of a presumed consent statute may create an atmosphere more favorable to the giving of consent, or physicians in presumed consent countries may ask for consent differently, phrasing it in terms of whether family members know of any objections to donation from the decedent rather than asking for their permission to retrieve organs. *See supra* text accompanying notes 70-73.

<sup>175.</sup> Healy, *supra* note 69, at 1038-43.

<sup>176.</sup> Chris Rudge, Organ Donation and the Law, 82 TRANSPLANTATION 1140, 1141 (2006); see also Healy, supra note 69, at 1040-41.

<sup>177.</sup> RAFAEL MATESANZ & CHRISTOPHER J. RUDGE, *The Acute Shortage of Donors: A UK and European Perspective, in* TRANSPLANTATION: A COMPANION TO SPECIALIST SURGICAL PRACTICE 19, 34-35 (John L.R. Forsythe ed., 3d ed. 2005).

likelihood that people document their wishes to donate while they are still alive. Public survey data finds a likelihood of donation close to 80%, but a documentation rate of just over 50%. If everyone who would like to donate signs an organ donor card, commits to organ donation on a driver's license, or otherwise agrees to be a donor, organ retrieval rates could increase by as much as 50%.<sup>178</sup>

Second, greater efforts should be made to overcome the reluctance of families to agree to donation. In many cases, it appears that refusals of consent are based on misconceptions (e.g., mistaken assumptions that organ donation violates religious scruples or that organ donation would affect the decedent's appearance at an opencasket funeral).<sup>179</sup> Broader implementation of successful approaches to discussions with families would be important.<sup>180</sup> For example, researchers have found that families are more likely to consent when the discussion about the person's death is separated from discussions about organ donation, when organ procurement professionals participate with hospital staff in the donation discussion, and when the request for donation takes place in a quiet, private setting.<sup>181</sup> Organ procurement professionals also are experimenting with a "presumptive approach" to consent for organ donation. Traditionally, health care professionals have taken a value-neutral, balanced approach in their discussions with family members.<sup>182</sup> Under the presumptive approach, the professional takes a value-positive, affirmative position about donation and encourages the family to agree to donation.183

It is difficult to see a revival of presumed consent in the near future, given its rejection by the 2006 UAGA. That said, attitudes might change, especially if the organ shortage continues to worsen. From the recent rise and fall of presumed consent, what lessons can

<sup>178.</sup> Changes in the law, particularly with the 2006 UAGA, are addressing the problem of family members overriding a decedent's documented desire to be an organ donor. REV. UNIF. ANATOMICAL GIFT ACT § 8(a) (2006).

<sup>179.</sup> Siminoff et al., *supra* note 84, at 973-76; Laura A. Siminoff et al., *Factors Influencing Families' Consent for Donation of Solid Organs for Transplantation*, 286 JAMA 71, 74 tbl.1 (2001).

<sup>180.</sup> David H. Howard et al., Does Quality Improvement Work? Evaluation of the Organ Donation Breakthrough Collaborative, 42 HEALTH SERV. RES. 2160, 2169-70 (2007); Howard K. Koh et al., A Statewide Public Health Approach to Improving Organ Donation: The Massachusetts Organ Donation Initiative, 97 AM. J. PUB. HEALTH 30, 31-34 (2007).

<sup>181.</sup> Gortmaker et al., *supra* note 68, at 214.

<sup>182.</sup> Sheldon Zink & Stacey Wertlieb, A Study of the Presumptive Approach to Consent for Organ Donation: A New Solution to an Old Problem, 26 CRITICAL CARE NURSE 129, 130 (2006).

<sup>183.</sup> *Id.* at 130-31. For a critique of the presumptive approach, see Robert D. Truog, *Consent for Organ Donation—Balancing Conflicting Ethical Obligations*, 358 NEW ENG. J. MED. 1209, 1210-11 (2008).

we draw about future proposals for presumed consent?

Inasmuch as the abandonment of presumed consent appears to reflect concerns about professionals abusing their presumed consent authority, and a system that may have placed a greater burden on minorities to supply needed organs and tissues, future policies must avoid these concerns.

Ensuring evenhandedness would require an important change in presumed consent laws. Instead of limiting presumed consent to persons under the custody of coroners or medical examiners, states could make all cadavers subject to presumed consent. While an important first step, more would need to be done to ensure evenhandedness. Physicians still could exercise their discretion in a biased way—even though all deceased persons would be subject to organ removal, doctors might be more likely to take organs from minorities.<sup>184</sup> To address this possibility, organ removal would have to be mandatory for decedents with viable organs in the absence of an objection, or careful monitoring of organ removal practices would be needed to detect any racial or other inappropriate biases in organ retrieval.

Preventing other kinds of abuse of authority is more challenging. After all, misconduct in the health care system is not limited to matters involving organs and tissues. Some doctors and hospitals defraud the Medicare and Medicaid systems; other doctors falsify research data.

A number of measures can reduce the possibility that organs would be wrongly taken for transplantation. In particular, it would be important to ensure that professional practices are open to public scrutiny. If transplant professionals cannot hide what they are doing, then it is much more difficult to engage in misconduct.

A good model is suggested by some of the requirements for conducting research on experimental therapies for people in lifethreatening situations where consent to participation in the research study is not feasible ("emergency research"). To allow for important research on treatments that would be provided to unconscious or otherwise incapacitated persons, the Food and Drug Administration created an exception to informed consent.<sup>185</sup> Taking some of the requirements that must be satisfied if informed consent cannot be obtained for emergency research.<sup>186</sup> we would end up with several

185. 21 C.F.R. § 50.24(a)(7) (2008).

<sup>184.</sup> Cf. Ira J. Chasnoff et al., The Prevalence of Illicit-Drug or Alcohol Use During Pregnancy and Discrepancies in Mandatory Reporting in Pinellas County, Florida, 322 NEW ENG. J. MED. 1202, 1204 (1990) (finding similar levels of drug use during pregnancy by blacks and whites, but that physicians are ten times more likely to report black women to health authorities).

<sup>186.</sup> Id.

requirements for a program of presumed consent to organ donation.

The transplant professionals implementing presumed consent in a community would have to:

• consult with representatives of the community before implementing presumed consent;

• disclose to the entire community the plans to implement presumed consent and discuss the implications of presumed consent for members of the community;

• publicly disclose anonymous data on a regular basis about the donors and recipients of organs under presumed consent; and

• establish an independent monitoring committee to exercise oversight of the presumed consent process.

Whether better implementation of presumed consent would lead to its acceptance is highly uncertain. Presumed consent has never been a significant basis for taking organs, even when allowed in the United States, or for that matter, in other countries. On the other hand, the continual worsening of the organ shortage should increase public receptivity to new approaches to increasing the organ supply. In the end, the resolution of this issue may come down to the question of whether alternative methods to increase the organ supply are more palatable to the public.<sup>187</sup>

<sup>187.</sup> For example, people might be more comfortable with financial incentives for organ donation since those preserve individual authority to decide, or with xenotransplantation (e.g., transplantation with pig kidneys or livers).