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## RETHINKING LEGISLATIVE CONSENT LAW?

*Michele Goodwin\**

*Each act of giving is unique, secret, spontaneous and inexplicable. There is no accounting for it, as there is no value in counterfeit coin.<sup>1</sup>*

*Transplantation cannot escape the income-based inequities that permeate the larger medical care system.<sup>2</sup>*

Carlos M. Gudino appeared twice in the *Los Angeles Times Newspaper*.<sup>3</sup> The first time was a kind of turning point or rebirth. He was only nineteen years old when he worked on a mural with Jesse Rojas, another young, aspiring artist, trying desperately to move beyond

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<sup>1</sup>Desmond Manderson, *Introduction: Tales from the Crypt—A Metaphor, An Image, A Story*, in *COURTING DEATH: THE LAW OF MORTALITY* 10 (Desmond Manderson ed., 1999) [hereinafter *COURTING DEATH*].

<sup>2</sup>Laurie Kaye Abraham, *MAMA MIGHT BE BETTER OFF DEAD* 183 (1993).

<sup>3</sup>Lisa Richardson, *Praise for His Art Keeps Young Muralist From Being Walled in by Harsh Gang Life*, L.A. TIMES, Nov. 27, 1992, at B1; Ralph Frammolino, *Harvest of Corneas at Morgue Questioned*, L.A. TIMES, Nov. 2, 1997.

the reach of Los Angeles gang life.<sup>4</sup> Their story, one of possible triumph, or at least of hope, was captured by a bold headline: "*Praise For His Art Keeps Young Muralist From Being Walled In By Harsh Gang Life.*"<sup>5</sup> A photograph memorialized Carlos' gaze as Jesse applied the final touches to the mural of the Madonna that Carlos helped to create.<sup>6</sup>

The Community Youth Gang Services and the Los Angeles Police Department helped to underwrite the project in an effort to bring calm to a community riddled by gang violence, teen unemployment, and drug transactions.<sup>7</sup> The mural is located at a corner in Los Angeles, California, where Wilmington meets G Street. It is considered a "tough place," where drug transactions occur nightly and trouble awaits. The project was aimed at helping the community overcome despair and transforming the lives of talented young men with a sincere interest at leaving "gangbanging behind."<sup>8</sup> Although the *L.A. Times* article focused considerably on Jesse's artistic talents, Carlos' youthful gaze was captured forever, giving the vision of hope.

Five years later, almost to the very day, in November 1997, Carlos again appeared in the same daily newspaper that captured him gazing at the mural of the Madonna.<sup>9</sup> Ironically, his brutal death from twelve bullet wounds to the head and chest, which had occurred earlier in the year, was not the focus of the second article. Instead, the article exposed the questionable harvesting of corneas at the local morgue without prior consent of deceased "donors" or their relatives.<sup>10</sup> The article raised questions about the roles of race, socio-economic status, and consent in this controversial process known as presumed or legislative consent.<sup>11</sup> The *Los Angeles Times* contacted Carlos M. Gudino's family as part of

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<sup>4</sup>Richardson, *supra* note 3.

<sup>5</sup>*Id.*

<sup>6</sup>*Id.* Richardson notes that "amid the gangbanging and hard living, looking down upon the frustrations of the jobless young men hungry for recognition, is a just-painted red, yellow, and green mural of the Virgin Mary." *Id.*

<sup>7</sup>*Id.*

<sup>8</sup>*Id.*

<sup>9</sup>Framolino, *Harvest of Corneas*, *supra* note 3.

<sup>10</sup>*Id.*

<sup>11</sup>*Id.*

a study it was conducting to determine whether or not families were aware that their loved-ones' corneas had been harvested and sold.

Like all the families in Ralph Frammolino's investigation, the Gudinos were unaware and shocked that cornea extraction had taken place.<sup>12</sup> Carlos corneas were harvested without his family's knowledge or permission.<sup>13</sup> The Gudinos were dismayed that the Los Angeles coroner's office had the authority to operate in what some have called a "clandestine" manner, referring to the legislation and process which presumes that one is willing to be a donor unless a prior refusal has been recorded, or relatives have objected.<sup>14</sup> Moreover, the fact that money was exchanged for his corneas seemed too reminiscent of slavery, generating potential sensitivity and paranoia about racial profiling, manipulation, and economic justice.

What made the Gudinos' situation somewhat unique and all the more troubling, as Carlos' sister, Maria, pointed out in an interview with Frammolino, was the fact that the family had registered their objection to any organ or tissue donation the morning after Carlos' death.<sup>15</sup> In fact, their objection, dutifully noted by an investigator from the coroner's office in a supplemental report, was quite specific: "Family is profoundly against ANY organ or tissue donation."<sup>16</sup>

However, the family's objection was too late; three hours earlier, Carlos' corneas had been harvested by the Doheny Eye and Tissue Bank under authorization of the coroner.<sup>17</sup> Doheny and the coroner's office had an arrangement whereby corneas were harvested and the coroner's office was paid "an average of about \$250 for a set of corneas, which [were] then sold to transplant institutions for a 'processing fee' of

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12 *Id.* Frammolino, author of the study involving over five hundred and seventy cases where corneas were removed without consent from donors or their families during a twelve month period, comments in his article that all the families "were shocked that they had not been asked or told."*Id.*

13 *Id.*

14 See *infra* Chapters IV and V.

15 Frammolino, *Harvest of Corneas*, *supra* note 3. Carlos, then aged 24 died shortly before nine o'clock in the evening on March 26, 1997 from head and chest wounds. The next day his sister called the morgue. She recalls, "my parents told me to let them know they didn't want any organs donated or anything." *Id.*

16 *Id.*

17 *Id.*

\$3,400."<sup>18</sup> Carlos' family learned the details of this transaction nearly eight months after his death.<sup>19</sup>

Frammolino's investigation, which involved reviewing 572 cases during a twelve-month period in which corneas were removed without family consent or knowledge, uncovered other unsettling information.<sup>20</sup> The overwhelming majority of the donors, seventy-two percent, were young homicide victims. Accident victims, the next largest donor pool, accounted for only sixteen percent.<sup>21</sup> Over eighty percent of the donors were of color (nearly sixty percent Latino and twenty-one percent African American).<sup>22</sup> Whites were only sixteen percent of the donor pool.<sup>23</sup> Were it not for Frammolino's investigation, Carlos' family, as well as others contacted for the study, may never have known about the legislative consent law or the removal of their loved ones' corneas.

## PART I. INTRODUCTION

Ironically, while the poor, and particularly those of color, reside at the margins of the global technological boom (many are unable to afford computers, do not have internet access, and have only limited exposure to computer technology), their bodies are nonetheless at the center of contemporary ethical debate. Accelerated growth in biotechnology and medical science is creating new uses for human tissues that were once presumed to have limited value beyond their original function and host.<sup>24</sup> Tissues, cells, and organs that once would have been buried at

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<sup>18</sup> *Id.* According to the L.A. TIMES investigation, the Doheny Eye & Tissue Transplant Bank paid more than one million dollars over a five-year period (1992-1997) to the Los Angeles County coroner's office for corneas "harvested without the permission or knowledge of the families of the dead." *Id.* Doheny's "markup" was more than 1200% of the purchase price--or gift--provided to the coroner's office, which was higher than usual, even by industry standards. *Id.*

<sup>19</sup> *Id.* Carlos Gudino died March 26, 1997. However, it was not until Frammolino contacted the family in the course of his investigation later that year that they became aware of the non-consensual cornea removal. *Id.*

<sup>20</sup> *Id.*

<sup>21</sup> *Id.*

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> See E. RICHARD GOLD, BODY PARTS: PROPERTY RIGHTS AND THE OWNERSHIP OF HUMAN BIOLOGICAL MATERIALS (1996); CHRISTOPHER WILLS, EXONS, INTRONS, AND TALKING GENES (1991); ROBERT SHAPIRO, THE HUMAN BLUEPRINT: THE RACE TO UNLOCK THE SECRETS OF OUR

death or disposed of after medical procedures have found new life in research laboratories and human hosts.<sup>25</sup> Through both transplantation and research, biological materials have proven invaluable in saving peoples' lives.<sup>26</sup>

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GENETIC CODE (1991). See also Kathleen M. Sullivan, *Unconstitutional Conditions*, 102 HARV. L. REV. 1415 (1989); Lawrence J. Nelson et al., *Forced Medical Treatment of Pregnant Women: "Compelling Each to Live as Seems Good to the Rest"*, 37 HASTINGS L.J. 703 (1986); John A. Robertson, *Posthumous Reproduction*, 69 IND. L.J. 1027 (1994); Michelle B. Bray, *Personalizing Personality: Toward a Property Right in Human Bodies*, 69 TEX. L. REV. 209 (1990); Roy Hardiman, *Toward the Right of Commerciality: Recognizing Property Rights in the Commercial Value of Human Tissue*, 34 UCLA L. REV. 207 (1986); Mary T. Danforth, *Cells, Sales and Royalties: The Patient's Right to a Portion of the Profits*, 6 YALE L. & POL'Y REV. 179 (1988); Erik S. Jaffe, Note, *She's Got Bette Davis's Eyes: Assessing The Nonconsensual Removal of Cadaver Organs Under The Takings and Due Process Clauses*, 90 COLUMB. L. REV. 528 (1990).

<sup>25</sup> Corneas and organs are most commonly associated with transplantation and the ability of science to use human biological material to improve the quality of one's life. However, transplantation of tissues from aborted fetuses, a technique with origins that predate organ transplantation, has also been characterized as effective. As early as the late nineteen twenties (1920s) doctors were transplanting aborted fetal tissues in diabetic patients in Europe. The first fetal tissue transplantation in the United States did not occur until a decade later, in 1939. By the nineteen-sixties in the United States, cornea, organ, and fetal tissue transplantations and experiments had been performed; some were done with greater frequency and efficacy than others, particularly with regard to corneas. Cornea transplantation predates both aborted fetal tissue and organ transplantation. As discussed *infra*, biotechnological advancements with immune suppressant drugs improved the efficacy of organ transplants. Nevertheless, some level of controversy has surrounded each of these procedures, either as to allocation and access, or to the ongoing debates about human dignity and the limits of morality in human experimentation. See ARTHUR CAPLAN, *AM I MY BROTHER'S KEEPER?* 40-49 (1997) (discussing fetal tissue transplantation and the controversy that erupted during former president George H. W. Bush's administration, in which a ban was imposed on "the use of federal funds to pay for research on transplants using fetal tissue," and discussing the ethical as well as political implications of fetal tissue research); GOLD, *supra* note 24, at 23-26 (discussing the "patient's body" and the "admixture of property law and the human body"); ROBERT M. VEATCH, *DEATH, DYING, AND THE BIOLOGICAL REVOLUTION: OUR LAST QUEST FOR RESPONSIBILITY* (1989); LINDA F. HOGLE, *RECOVERING THE NATION'S BODY: CULTURAL MEMORY, MEDICINE, AND THE POLITICS OF REDEMPTION* (1999) (discussing how the Schutztaffel, or SS, in Nazi Germany, became fascinated with capabilities of medicine and research on the human body).

<sup>26</sup> UNITED NETWORK FOR ORGAN SHARRING, 1998 ANNUAL REPORT OF THE U.S. SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS AND THE ORGAN PROCUREMENT AND TRANPLANTATION NETWORK (1998) [Hereinafter 1998 ANNUAL REPORT]; See also David E. Jefferies, *The Body as Commodity: The Use of Markets to Cure the Organ Deficit*, 5 IND. J. GLOBAL LEGAL STUD. 621, at 622 (1998); Marla Clark, *Solving the Kidney Shortage Crisis Through the Use of Non-Heart-Beating Cadaveric Donors: Legal Endorsement of Perfusion as a Standard Procedure*, 70 IND. L.J. 929 (1995); Jaffe, *supra* note 24; Beth Brandon, Note, *Anencephalic Infants As Organ Donors: A Question of Life or Death*, 40 CASE W. RES. L. REV. 781 (1990). This year an estimated three hundred thousand people worldwide will receive an

Nevertheless, thousands of Americans die annually from illnesses involving failed organs.<sup>27</sup> Of those who die, some are on waitlists for organs<sup>28</sup> while many others are not.<sup>29</sup> Despite technological advancements, including the growing field of organ transplantation, the limited supply of human biological materials has not kept pace with an overwhelming demand.<sup>30</sup> How to resolve, or even characterize, the great demand for organs has been a point of contention for ethicists, politicians, and the medical and legal communities.<sup>31</sup> Furthermore, even though other technologies seem promising in addressing

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organ transplant. However, that number is overshadowed by the thousands who die each year while languishing on sometimes stagnant waitlists. Each year the number of patients waiting for organ donations increases, along with the number of patients who are placed on dialysis or other treatments or procedures in lieu of organ transplantation. See Ellis Interview *infra* note 224.

<sup>27</sup>1998 ANNUAL REPORT, *supra* note 26 at 15-17 (detailing the death rates for the incidence and prevalence cohorts on the waiting lists for organs).

<sup>28</sup>*Id.*

<sup>29</sup>This may best be illustrated by treatment of kidney failure. For example, not all patients with kidney failure meet the criteria for organ transplantation. As discussed *infra*, a variety of factors contribute to why some patients are placed on an organ waitlist while others are not. See Kevin McCoy, *Deadly Disparity in Transplants: Blacks & Hispanics Deprived*, DAILY NEWS (NEW YORK), Aug. 8, 1999, at 6. McCoy's investigative study on organ transplantation in New York revealed racial and socio-economic disparities in the organ transplantation referral process. He reported that the main factor blocking blacks and Hispanics from transplants was that they weren't on organ waiting lists. He suggests that this occurs because their doctors do not refer them to transplant centers or that they are referred too late or because of lacking health insurance. *Id.* See also Rod Watson, In Blacks, Tragic Mistrust of Medicine, THE BUFFALO NEWS, Feb. 22, 2001, at 1B (discussing the affects of race, racism and perception in the organ transplantation). A kidney patient who is not referred to a waitlist by her physician can be sustained nonetheless through dialysis, a process that uses a machine to substitute for the function of the kidney. However, dialysis is expensive and can significantly alter one's lifestyle and quality of life. Because dialysis usually requires a patient to be connected to a machine three days per week, for several hours each time, it is often less desirable than actually having an organ transplantation. Associated Press, *Two Studies Find Disparities in Who Gets New Kidneys*, ST. LOUIS POST-DISPATCH, Nov. 25, 1999, at A8 (noting that kidney patients who undergo dialysis at commercial centers are less likely to get on a transplant waiting list--and more likely to die--than patients at nonprofit institution, according to a study authored by Dr. Pushkal Garg of Johns Hopkins University. Also discussing two studies revealing racial disparities in kidney transplantation. However, it is debatable whether and how the option of transplantation is presented to all patients when such procedures may be medically viable.

<sup>30</sup>*E.g.*, GOLD *supra* note 24, at 141-42.

<sup>31</sup>See generally ORGAN TRANSPLANTATION: MEANINGS AND REALITIES (Stuart J. Youngner et al. eds., 1996).

America's organ shortage, particularly stem cell therapy<sup>32</sup> and even xenotransplantation,<sup>33</sup> the therapies are too premature to guarantee success, and thus cannot resolve the present shortage of transplantable organs. If transplanting human biological materials is the best answer to replacing failed organs, how to increase the supply of viable organs is a question of critical importance.

Part II of this article provides an overview of the contemporary questions surrounding race and the organ allocation process. It attempts to contextualize the racial, political, economic, and social realities in the organ transplantation process by first exploring perceptions of health and the black body. Part III defines and analyzes legislative consent policies. Also in Part III, eye bank directors from across the country offer their opinions about legislative consent policies. Part IV challenges the moral framework of presumed consent. It argues that presumed consent is difficult to justify, particularly because of its very real racial implications in the United States. Indeed, the practice is difficult to support even when based on a notion of social compact theory because of disparities that have a significant racial impact on organ allocation. This article concludes in Part V by arguing that because of the attendant health, ethical, and moral concerns surrounding presumed consent, and evidence that it does not comport with notions of distributive justice, legislative consent is not the preferred alternative or solution for increasing the supply of organs for transplantation.

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<sup>32</sup>This new technology would allow the body to "regrow" organs rather than have a foreign organ transplanted into the body. See Sarah A. Webster, *New Hope for Sick Children: \$ 1M Gift Launches Blood Cell Center: Karmanos Cancer Institute Will Store Stem Cells that Fight Minority Diseases*, THE DETROIT NEWS, December 9, 1999, at A1 (Potentially thousands of children with blood diseases could be helped if the supply of cord blood is increased). However, Webster notes because umbilical cords contain only about six tablespoons of stem cells, children are the only candidates for such donations. Doctors need a certain number of stem cells for the weight of the patient. About 800 pediatric patients worldwide have received transplants of cord blood stem cells.

<sup>33</sup>For an explanation of xenotransplantation, see Jack M. Kress, *Xenotransplantation: Ethics and Economics*, 53 FOOD DRUG L.J. 353 (1998). Kress discusses xenotransplantation, noting that "for the [Department of Health and Human Services], 'xenotransplantation' refers to any procedure that involves the use of live cells, tissues, or organs from a non-human animal source, that are injected, implanted, or transplanted into a human being." *Id.* at 354.



## PART II. RACIAL BIAS IN HEALTHCARE: THE UNEXPLORED FRONTIER

Although studies indicate that as many as eighty-five percent of Americans support organ donations, fewer than twenty percent actually carry donor cards.<sup>34</sup> The reluctance to donate, as discussed *infra*, has been attributed to distrust of the medical establishment and racial and religious concerns,<sup>35</sup> as well as other considerations.<sup>36</sup> Arguably, efforts to address some of these issues have yielded some gains in the number of transplantable organs. However, the overall increase in viable organs has been limited and cannot keep pace with the great demand, particularly for groups of color.

While equity and access issues have emerged in the medical literature, within the context of the law, racial biases and disparities in healthcare seem to be relatively unexplored.<sup>37</sup> Little legal scholarship has been devoted to the intersection of race, healthcare, and the law, particularly regarding sophisticated technologies such as organ transplantation.<sup>38</sup> One might argue that distributive justice in healthcare was one of the most important areas that was overlooked or not adequately addressed during America's civil rights era.

Race, gender and socio-economic factors should not be ignored in the discussion about organ allocation and transplantation, but rather should motivate interest and research. However, the ability to truly understand the implications of race, gender, and class discrimination with regard to healthcare access, and particularly organ transplantation,

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<sup>34</sup>*Organ Allocation: A National Roundup*, AM. HEALTH LINE, Aug. 11, 1999 (noting the paradox).

<sup>35</sup>Norma Adams-Wade, *A Life-Giving Change; Officials Hope Rule Boosts Minorities' Organ Donations*, DALLAS MORN. NEWS, November 29, 1999, at 17A.

<sup>36</sup>*See infra* notes, 39-40.

<sup>37</sup>Barbara Noah, *Racial Disparities in The Delivery of Health Care*, 35 SAN DIEGO L. REV. 135 (1998). Noah argues that "the role that conscious or unconscious racial bias may play in the health care context has, by comparison, attracted comparatively little public attention." *Id.* at 137.

<sup>38</sup>*Id.* *See generally* Vernellia R. Randall, *Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191 (1996). Professor Randall's research examines the intersection of race, law and medicine. She comments on historical and contemporary uses of racism as an institutional construct that limits African American access to healthcare and life-saving treatments. She also points to the need for greater inclusion and visibility of people of color in the study of the intersection of medicine and law.

may be constrained by the limited scholarship that is currently available on the topic. Empirical studies on the effects of race and social status discrimination in the distribution of organs generally are not available, demonstrating, perhaps, a lack of interest in the topic on the part of mainstream bioethicists. On the other hand, the noticeable absence of research studies in this area might be attributed to an unawareness of the issue's importance, the inherent complications of and obstacles to collecting data, or the difficulty of identifying and articulating the more subtle nuances of racism and poverty in healthcare. Some have suggested that most medical school faculty and students are culturally unequipped and lack a competency in working with diverse populations. This, some observe, is exacerbated by the stunningly low percentage of African Americans graduating with medical degrees.<sup>39</sup>

An unprecedented demand for organs, particularly from communities of color, and the potential to save lives through available technology has forced a fundamental reconsideration of the legal, ethical, medical and moral issues associated with organ transplantation.<sup>40</sup> Ethical questions abound as legislators, ethicists and

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<sup>39</sup>See Henry Lewis, III, *Different Prescriptions for Florida's Shortage of Doctors; FAMU Deserves Larger Role in State's Medical Education*; THE TAMPA TRIBUNE, Mar. 20, 1999, at 15 (articulating the need for an additional medical school in Florida which would enroll more students of color, noting that minorities are underrepresented at all levels of medicine). Lewis report found that in 1997, black Americans, Hispanics and American Indians/Alaska natives represented approximately 23.6 percent of the population, but only 12.2 percent of enrollees in allopathic medical schools were underrepresented minorities. *Id.* Note also that between 1996 and 1997 there was over a seven percent (7%) decline in underrepresented minority new entrants to U.S. medical schools. *Id.*

The American Association of Medical Colleges offers far more dramatic statistics. Their web page notes that, minority enrollments in U.S. medical schools reached their peak in 1975, when minorities represented 8.1 percent of the total student body. Since then, however, a leveling-off effect has dominated, and no significant increase in the number of underrepresented minorities entering medical school has occurred. ASS'N OF AM. MED. COLLEGES, AAMC STATEMENT ON MED. EDUC. OF MINORITY GROUP STUDENTS (June 1987), at <http://www.aamc.org/meded/minority/recruit/statemin.htm>. See also *Why a Nationwide Ban on Race-Conscious Admissions Will Sharply Curtail Black Enrollments as the Nation's Highest-Ranked Medical Schools*, 23 J. BLACKS IN HIGHER EDUC. 22 (Spring 1999); *Minority Entrants to California Med Schools Down 32 Percent*, MED. & HEALTH, Apr. 26, 1999, available in 1999 WL 10391837.

<sup>40</sup>See Ralph Frammolino, L.A. Coroner Alters Policy on Corneas, L.A. TIMES, Nov. 4, 1997 at A1; Frammolino, *Harvest of Corneas*, *supra* note 3; *Official Knew About Cornea Removals*, LAS VEGAS REV.-J. AND LAS VEGAS SUN, Nov. 23, 1997, at 11B; Betsy Butgereit, *Plan Would Require Cornea Removal OK*, BIRMINGHAM NEWS (Alabama), Feb. 17, 1998, at

organ procurement organizations debate the best methods to increase organ supply.<sup>41</sup> Among the possible solutions currently debated to alleviate the demand for organs are two provocative possibilities: presumed consent and commercialization. Neither method is presently used with regard to organ procurement in the United States; a federal ban prohibits the sale of organs,<sup>42</sup> and presumed consent is used only with regard to corneas and eye tissues in some states.<sup>43</sup> Nonetheless, both methods are touted as possible solutions to what politicians are calling an "organ crisis." This article will explore organ allocation and transplantation, specifically addressing presumed or legislative consent policies and the attendant difficulties of justifying their use through social contract theory.

Presumed consent is a highly controversial method for remedying organ and tissue shortages, as evidenced by the fact that it has been plagued by legal and ethical problems when used with regard to cornea removal.<sup>44</sup> The statutes authorizing legislative consent for use of corneas permit the medical examiner or justice of the peace, or their agents, to extract the corneas and sometimes other tissue (including the entire eye) from cadavers if an autopsy is scheduled to be performed, and no objection to the removal is known.<sup>45</sup> The medical examiner

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1A [hereinafter *Cornea Removal OK*]; Betsy Butgereit, *Cornea Controversy: Eye Banks Don't See Eye-to-You on Laws*, BIRMINGHAM NEWS (Alabama), Feb. 16, 1998, at 1A [hereinafter *Controversy*]; Celia Sibley, *Widow Wins Unwilling Eye Donor Suit*, ATLANTA J., Jan. 1, 1998, at A01.

<sup>41</sup>Among the ethical considerations at issue with respect to organ transplantation are devotion to patient's goals, distributive justice, contributive justice, and preservation of human dignity. For a general discussion of these considerations, see John J. Paris, *Managed Care, Financial Incentives, and Cost Control: Shifts in the Ethical Focus of Health Care Delivery* (unpublished manuscript, on file with author); Edmund Pellegrino, *Rationing Health Care: The Ethics of Medical Gatekeeping*, 2 J. CONTEMP. HEALTH L. POL'Y 23-45 (1986); CAPLAN, *supra* note 25; NORM DANIELS, *JUST HEALTH CARE* (1985).

<sup>42</sup>See The National Organ Transplantation Act, 42 U.S.C. 273 (1994) [hereinafter *NOTA*]; The Organ Procurement Transplantation Network was established out of 42 U.S.C. 274 (a)-(b) (1994).

<sup>43</sup>See *Bad Publicity Could Reduce Cornea Supply*, REV. OF OPHTHALMOLOGY, Dec. 1997, at 3.

<sup>44</sup>*Id.*

<sup>45</sup>For an example of a presumed consent or "medical examiner" or "legislative consent" statute, see Md. Statute 4-509.1 When Chief Medical Examiner or His Deputy Or Assistant May Provide Cornea for Transplant.

may delegate this right to a physician or eye bank.<sup>46</sup> Its proponents suggest that presumed consent increases tissue supply while respecting "donor" autonomy and individual choice by virtue of an "opt out" provision for prior refusal.<sup>47</sup>

Medical examiner laws were passed in twenty-eight states, and most were promulgated during the mid-nineteen eighties (1980s), a time that some commentators recall as being marked by violence and death in urban communities of color.<sup>48</sup> Some eye bank officials, including those from California and Alabama, credit presumed consent laws for the increase in corneal tissues available for transplantation in their states.<sup>49</sup> Indeed, data from these states indicate that corneas available for transplantation did increase, particularly as more tissues were available from victims of trauma and homicides.<sup>50</sup> In some instances, surpluses were created which allowed tissue banks to sell "left-over" tissues to medical research laboratories, sometimes at tremendous markups.<sup>51</sup>

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<sup>46</sup>*Id.*

<sup>47</sup>See CAPLAN, *supra* note 25, at 125.

<sup>48</sup>See DeWayne Wickham, *Americas Smaller Communities Getting Taste of Urban Violence* GANNETT NEWS SERVICE, May 25, (citation omitted) (noting rise in violence in the 1980s); Gabriel Escobar, *Deaths Pose Continuing D.C. Mystery; City Carries Hundreds of Undetermined Cases, Muddying Vital Statistics*, WASH. POST, December 22, 1997, at A1 (commenting on the rise in urban violence in the 1980s and that many of the deaths of black urban Americans from that era remain unsolved); Glen Loury, *The Impossible Dilemma*, THE NEW REPUBLIC, January 1, 1996, at 21 (noting that the murder rate among black youths (persons under age 20), which was already three times that of white youths in 1986, doubled in the five years between 1986 and 1991, while the rate among whites remained unchanged). See also Darryl Fears, *Urban Spotlight: Is Atlanta the Next Detroit?* THE ATLANTA JOURNAL AND CONSTITUTION, December 18, 1994, at D1 (pointing out that in the early 1980s, the homicide rate soared). Fears reports that between 1983 and 1987, more than 700 people were slain each year. On No Crime Day in Detroit - a 1986 event sponsored by basketball star Isaiah Thomas to prove his city was still safe - a police officer was shot dead. *Id.*

<sup>49</sup>Telephone interview with Doyce Williams, Executive Director of the Alabama Eye Bank (Feb. 21, 2000) [hereinafter Williams Interview I]. Mr. Williams expressed his great support for presumed consent legislation, and asserted that legislative consent had a very positive influence on the number of corneas that were made available for transplantation. See also Frammolino, *L.A. Coroner*, *supra* note 40.

<sup>50</sup> Telephone Interview with Doyce Williams, Executive Director of the Alabama Eye Bank (Feb. 23, 2000) [hereinafter Williams Interview II].

<sup>51</sup> See Frammolino, *Harvest of Corneas*, *supra* note 3.

However, whether or not presumed consent has always worked effectively is debatable.<sup>52</sup> Some concerns of opponents of presumed consent are highlighted by problems regarding tissue extractions without consent: the possibility of transmitting communicable diseases where health or social histories have not been obtained, transplanting low-quality biological materials, and failure to obtain consent. They also argue that any policy that limits donor autonomy and ignores family consent is fundamentally flawed.<sup>53</sup>

Nonetheless, presumed consent proponents argue that saving the living should be society's greatest concern and presumed consent is a method for doing just that. Furthermore, some commentators point out that many of the legislative consent statutes offer a right for the donor to refuse the extraction. The "opt-out" provision, they say, actually allows for one to revoke consent.

Whether an increased supply of organs should be the prime or sole focus of an ethical and equitable procurement policy seems a relevant and timely question.<sup>54</sup> Further, it appears debatable whether other procurement methods, which are less intrusive with regard to privacy and autonomy, would not prove more successful. Some eye bank directors interviewed for this study strongly suggest that presumed consent might not be the best method for increasing the supply of healthy organs and tissues.<sup>55</sup> They argue that eye banks using strict

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<sup>52</sup>Frammolino, *L.A. Coroner*, *supra* note 40. Frammolino highlights the controversy surrounding cornea transplantation and presumed consent legislation, noting the potentials for abuse of the policy and for racial discrimination. *Id.*

<sup>53</sup>*See, e.g.*, Interview with Mark Larson, Executive Director of the Eyebank of Wisconsin, in Madison, Wis. (Feb. 21, 2000) [hereinafter Larson Interview]; Interview with Dr. Jim Martin, Executive Director of the Louisville Eye Bank (Mar. 1999 and Aug. 1999) [hereinafter Martin Interview].

<sup>54</sup>Tissue Banks International (TBI) and the Doheny Eye Bank, which serve Los Angeles, have been criticized by former employees, ethicist, and investigative news programs like *20/20* and the *L.A. TIMES* for their eagerness to increase supply of cornea tissue, sometimes without regard for family consent, health factors or social criteria which would restrict certain corneas from entering the stream of supply. *Id.*

<sup>55</sup>*See* Cornea Research Interview Notes and Transcripts (on file with author). Interviews were conducted with directors of eye banks representing Wisconsin, Kentucky, Arkansas, northern Florida, Michigan, Illinois, northern Ohio, Indiana, Massachusetts, New Hampshire, Rhode Island, Vermont, and New Orleans. Attempts were made to interview eye bank representatives or directors representing Georgia, California, Maryland, Texas, and Minnesota. *But see* Williams Interview I, *supra* note 49; Interview with Mary Jane O'Neil, Executive Director of Eye Bank Sight Restoration in New York. Both O'Neil and Williams support

consent policies with effective educational programming also experience surpluses in donation.<sup>56</sup>

### PART III. UNDERSTANDING LEGISLATIVE (OR PRESUMED) CONSENT

Consent, an essential moral and ethical principle in organ donation, has nevertheless been perceived as problematic in the mass procurement of organs.<sup>57</sup> The 1968 Uniform Anatomical Gift Act (UAGA) failed to clarify key issues with regard to consent,<sup>58</sup> one of which was connected to autopsies and coroner authority.<sup>59</sup> The Act did not offer a model to

presumed consent laws and believe that it would greatly benefit their states. Neither state presently uses legislative consent to procure eye tissues.

<sup>56</sup>See Cornea Research Interview Notes and Transcripts, *supra* note 54.

<sup>57</sup>Linda C. Fentiman, *Organ Donation as National Service: A Proposed Federal Organ Donation Law*, 27 SUFFOLK U. L. REV. 1593, 1599 (proposing presumed consent system that would avoid consent, and arguing that "physicians would no longer need to confront a grieving family with the need to make a quick decision about organ donation"); Jaffe, *supra* note 24, at 535 (stating that "one significant barrier was perceived to be the difficulty of obtaining consent for organ donation").

<sup>58</sup>See Note, *Regulating the Sale of Human Organs*, 71 VIRGINIA L. REV. 1015, 1016, 1016 n. 14 (1985)[hereinafter *Sale of Human Organs*]; Note, *Regulating The "Gift of Life"—The 1987 Uniform Anatomical Gift Act*, 65 WASH. L. REV. 171, 176 (1990) [hereinafter *Regulating The Gift of Life*].

<sup>59</sup>UAGA (1968) 7(d) ("The provisions of this Act are subject to the laws of the state prescribing powers and duties with respect to autopsies.").

The autopsy or medical examiner provisions are referred to as "legislative consent" statutes by most of the eye bank directors interviewed in this study. The legislative consent statutes operate through medical inquest or autopsy as discussed *infra*. Autopsies, while now common, are mandatory only in certain circumstances. These laws operate through mandatory medical examiner inquiry or investigation (as opposed to a family member requesting the procedure). These statutes however refer to "autopsy" as the mandatory medical examiner investigation. It should therefore not be confused with routine autopsies that a private individual may request, but which the state is not investigating. See also TEX. HEALTH AND SAFETY 693.012, the Texas statute authorizing legislative consent, reading in part:

Section 1. On a request from an authorized official of an eye bank for corneal tissue, a justice of the peace or medical examiner may permit the removal of corneal tissue if:

- (1) the decedent from whom the tissue is to be taken died under circumstances requiring an inquest by the justice of the peace or the medical examiner;
- (2) no objection by a person listed in Section 2 of this Act is known by the justice of the peace or the medical examiner; and
- (3) the removal of corneal tissue will not interfere with the subsequent course of an investigation or autopsy, or alter the postmortem facial appearance.

address posthumous handling of human bodies or parts thereof.<sup>60</sup> Thus, questions of organ sales or posthumous appropriation remained.<sup>61</sup> Each state was left to its own interpretation of the conditions necessary to compel state action on a corpse.<sup>62</sup> While consent was important for developing cultural trust in the donation and transplantation process, it nonetheless has become perceived as an obstacle.<sup>63</sup> Jaffe noted that consent "soon became a hindrance as the success of organ transplantation increased."<sup>64</sup> Others troubled by the consent requirement argued that consent impedes the progress of organ transplantation by limiting the number of organs made available.<sup>65</sup>

Limited consent strategies were developed--both to address methods for posthumous handling of the body and also to alleviate tissue and organ shortage. Part III of this article attempts to educate the reader about legislative consent policies, and the moral and ethical issues that surround limited (or no) consent measures. Legislative consent is presently used only with eyes, eye tissues, and corneas in the United States, and only in fewer than a dozen states (although nearly thirty states have laws authorizing the medical examiner to remove eyes without consent).

However, some commentators, including Linda Fentiman, have proposed organ donation as a national service, and support legislative consent with the possibility of opting out.<sup>66</sup> States that have adopted

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<sup>60</sup>See UAGA (1968) 7 (d).

<sup>61</sup>In fact, the 1968 UAGA drew staunch criticism from commentators disappointed with its ambiguities on organ retrieval without consent and organ sales. Jaffe, *supra* note 24, at 534 & n. 30.

<sup>62</sup>UAGA (1968) 7(d) (stating that the provisions of the UAGA are subject to the individual laws of states prescribing powers and duties with regard to autopsies); Jaffe, *supra* note 24, at 534 ("the UAGA (1968) had no effect on the normal duties of the coroner, however, since the Act was explicitly made subject to the existing state autopsy laws").

<sup>63</sup>Fentiman, *supra* note 57, at 1599; Jaffe, *supra* note 24, at 535.

<sup>64</sup>*Id.*

<sup>65</sup>Williams Interview II, *supra* note 50. Williams argues that donor registration is too bureaucratic and that lives could be saved with legislative consent to harvest organs. See also Mark F. Anderson, *The Future of Organ Transplantation: From Where Will New Donors Come, To Whom Will Their Organs Go*, 5 HEALTH MATRIX 249, 258-70 (1995). Anderson notes that one of the two claims made by proponents of presumed consent centers on alleviating the burden of consenting to something which they otherwise would support, thereby producing "greater numbers of organs for transplantation." *Id.* at 259.

<sup>66</sup>Fentiman, *supra* note 57.

this model are presented with significant moral and ethical problems, particularly since these laws operate through medical examiner inquiries into homicides, trauma, poisonings, and deaths that happen disproportionately in urban and poor communities.<sup>67</sup> Only a few courts have addressed the legality of these state statutes because so few cases have been brought to challenge such laws.<sup>68</sup> According to Mark Larson, Executive Director of the Eyebank of Wisconsin, some of the reasons for this might be the fact that people are generally unaware of presumed consent statutes in their states, and the fact that it is difficult to detect when corneas have been removed.<sup>69</sup> Presumed consent presents too many moral and ethical problems to justify its use, even under a social contract analysis as discussed in Parts III and IV of this article.

Of the fifteen eye bank directors or administrative staff interviewed for this study only three shared the opinion that the benefits of legislative consent policies outweighed obtaining donor consent, or for that matter, collecting medical history.<sup>70</sup>

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<sup>67</sup>Anderson, *supra* note 65, at 268 (discussing the purpose of autopsies to investigate the purpose of death and that state statutes authorize medical examiners to perform such inquiries without consent for "non-homicidal traumatic death" and "suspected homicides"). However, relatively little scholarly attention has been given to presumed consent and its impact on fragile communities (the poor, urban, of color, homeless, etc.).

<sup>68</sup>Jaffe, *supra* note 24, at 538.

<sup>69</sup>Larson Interview, *supra* note 53.

<sup>70</sup>Those interviewed include: Mary Jane O'Neil, Executive Director, Eye Bank Sight Restoration (New York, N.Y.); Florence Johnston, President & CEO, Midwest Eye Bank (Mich.); Tom Buckley, Executive Director, New England Eye and Tissue Transplant Bank (Boston, Mass.); Donica Davis, Hospital Development Coordinator, Tennessee Eye Bank; Mark Larson, Executive Director, The Eyebank of Wisconsin (Madison, Wis.); Dr. Jim Martin, Executive Director of Louisville Eye Bank (Louisville, Ky.); Gene Reynolds, Technical Director, Alabama Eye Bank; Kristen McCoy, Laboratory Director Illinois Eye Bank; Maurice Van Zance, Executive Director, Indiana Transplant Program; Chey Greiger, Administrator, Southern Eye Bank (New Orleans, La.); Doyce Williams, Executive Director, Alabama Eye Bank; David Sierra, Hospital Development Technical Director, North Florida Lions Eye Bank (Jacksonville, Fla.). Interviews were also conducted with representatives from Tissue Banks International (Md.) and The Eye Bank Association of America. Attempts were made to interview eye bank officials in California and Washington, D.C.; however, calls made in February and March (2000) were not returned. A concerted effort was made to interview officials from states with legislative consent provisions.



### *Definitions & New Directions*

In an effort to procure organs that otherwise would not have been donated, two donation models have developed: legislative consent, also referred to as presumed consent; and "reasonable efforts to obtain consent."<sup>71</sup> Legislative consent basically assumes legislative authority

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<sup>71</sup>UAGA (1987) 4. Unlike most presumed consent laws, the UAGA (1987) applies to all organs. However, unlike traditional presumed consent laws, a reasonable effort to allow for consent is encouraged in the statute. Section 4(a)(2) requires that the medical examiner "make a reasonable effort . . . to locate and examine the decedent's medical records and inform the next of kin." Nevertheless, enforcement of this provision seems difficult to monitor and Frammolino's investigation discussed in the Introduction illuminates the fact that requests are not always pursued prior to tissue harvesting. See Frammolino, *Harvest of Corneas*, *supra* note 3. Note, however, that California, the state in question, both adopted the UAGA (1987) and has presumed consent legislation. See also State of Wisconsin Statutes 157.06 Uniform Anatomical Gift Act (relevant portion):

(4) Authorization By Coroner or Medical Examiner.

(a) The Coroner or medical examiner may release and permit the removal of a part from, a decedent within that official's custody, for transplantation or therapy, if all of the following apply:

(1) The official has received a request for the part of the body from a hospital, physician or procurement organization.

(2) The official has made a reasonable effort, taking into account the useful life of the part of the body, to locate and examine the decedent's medical records and inform individuals listed in sub. (3)(a) of their option to make, or object to making, an anatomical gift.

(3) The official does not know of a refusal or contrary indication by the decedent or of an objection by an individual having priority to act as listed in sub. (3)(a)

(4) The removal will be by a physician, except that in the case of eyes, by a physician or by an enucleator.

(5) The removal will not interfere with any autopsy or investigation.

(6) The removal will be in accordance with accepted medical standards.

(7) Cosmetic restoration will be done to the decedent's body, if appropriate.

(b) An official releasing, and permitting the removal of a part of, a human body shall maintain a permanent record of the name of the decedent, the name of the person making the request, the date and purpose of the request, the part of the body requested and the name of the person to whom it was released.

Wisconsin has a typical autopsy law with the following provisions:

The following deaths occurring at Wisconsin hospitals must be reported to the coroner:

a. All deaths in which there are unexplained, unusual, or suspicious circumstances

b. All homicides.

c. All suicides.

d. All deaths following an abortion.

e. All deaths due to poisoning, whether homicidal, suicidal, or accidental.

over a corpse that appears before the medical examiner, justice of the peace, or coroner, pursuant to a mandatory autopsy or investigation.<sup>72</sup> Required request is a provision related to presume consent that allows for nonconsensual removal of body parts, but requires that an effort be made to contact the decedent's nearest relative for consent prior to organ harvesting.<sup>73</sup> Metaphorically, the consent process happens in two spheres: first, the legislature authorizes the coroner to remove the tissue; then coroner authorizes release of the tissue for particular purposes.

Both models have yet to fulfill the legislative expectations and increase in organ procurement that was hoped for over fifteen years ago. They also further exacerbate the tension surrounding organ donation by compounding the shortfall in organ and tissue supply with uneasily resolvable moral and ethical problems.<sup>74</sup> Is it ethical to remove one's eyes or other tissues without obtaining prior consent from the donor? How does a homeless person opt-out? Can the legislature have final authority over one's body? Obviously, it can with regard to criminal prosecutions. Indeed, capital punishment is authorized through state legislation and involves taking the life of another. And yet, legislative consent, for purposes of donation, is different; its purpose is

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f. All deaths following accidents (of any kind) whether the injury is or is not the primary cause of death.

g. When there was no physician, or accredited practitioner of a bona fide religious denomination relying upon prayer or spiritual means for healing in attendance within 30 days preceding death.

h. When a physician refuses to sign the death certificate.

When, after reasonable efforts, a physician cannot be obtained to sign the medical verification as required under Section 69.18 (2)(b) or (c) of the Wisconsin Statutes within 6 days after the pronouncement of death or sooner under circumstances which the coroner or medical examiner determines to be an emergency.

<sup>72</sup>See *supra* note 59.

<sup>73</sup>Jaffe, *supra* note 24, at 537 & n.41.

<sup>74</sup>Larson Interview, *supra* note 53. Larson strongly opposes legislative consent. In our interview, he emphasized the moral and potential health risks involved in procuring and transplanting tissues without consent and communication with families. He acknowledges that autopsies will generally destroy corneas (because they are pierced to retrieve vitreous fluid), and that the physical impairment is less offensive than the immorality of taking something so intimate and personal off of someone's family member. *Id.*

not to punish, but rather to give the gift of sight, according to Doyce Williams.<sup>75</sup>

### Eye Bank Directors Speak Out: Is Legislative Consent Ethical?

Both legislative consent and requirements for reasonable efforts to obtain consent effectively operate to reduce or remove donor authority to grant consent prior to harvesting of body parts, with legislative consent being the more extreme of the two.<sup>76</sup> First, legislative consent, developed initially in Maryland with the passage of its presumed consent law in 1975,<sup>77</sup> and passed in twenty-eight states<sup>78</sup> (with nine

<sup>75</sup>Williams Interview, *supra* note 65.

<sup>76</sup>Phyllis Coleman, "Brother Can You Spare a Liver?" *Five Ways to Increase Organ Donation*, 31 VAL. U.L. REV. 1, 18 (1996) (commenting that "presumed consent represents a more extreme proposal than required request").

<sup>77</sup>See 40509.1 (1982 Md. Laws Section 2 ch. 73; 1982, ch. 770 4). Titled: When Chief Medical Examiner or his deputy or assistant may provide cornea transplant, describes the statutory requirements and provisions for legislative consent:

(a) Requirements--In any case where a patient is in need of corneal tissue for a transplant, the Chief Medical Examiner, the deputy chief medical examiner, or an assistant medical examiner may provide the cornea upon the request of the Medical Eye Bank of Maryland, Incorporated under the following conditions:

- (1) The medical examiner has charge of a decedent who may provide a suitable cornea for transplant;
- (2) An autopsy will be required;
- (3) No objection by the next of kin is known by the medical examiner; and
- (4) Removal of the cornea for transplant will not interfere with the subsequent course of an investigation or autopsy or alter the postmortem facial appearance.

(b) Liability of Medical Examiner.--The Chief Medical Examiner, the deputy chief medical examiner, an assistant medical examiner, and the Medical Eye Bank of Maryland, Incorporated are not liable for civil action if the next of kin subsequently contends that authorization of that kin was required.

<sup>78</sup>ARIZ. REV. STAT. ANN. 36-851 to -852 (1986 & Supp.1989); ARK. CODE ANN. 12-12-320 (1987); CAL. GOV'T CODE 27491.46-47 (West 1988); COLO. REV. STAT. 30-10-621 (1986); CONN. GEN. STAT. ANN. 19a-281 (West 1986); DEL. CODE ANN. tit. 29, 4712 (Supp.1988); FLA. STAT. ANN. 732.9185 (West Supp.1989); GA. CODE ANN. 31-23-6 (1985); HAW. REV. STAT. ANN. 327-4 (1988); IDAHO CODE 39-3405 (Supp.1989); ILL. ANN. STAT. ch. 110 1/2, 351-354 (Smith-Hurd Supp.1989); KY. REV. STAT. ANN. 311.187 (Michie Supp.1988); LA. REV. STAT. ANN. 17:2354.1-3, 33:1565 (West 1982, 1988 & Supp.1989); MD. EST. & TRUSTS CODE ANN. 4-509.1 (Supp.1989); MASS. ANN. LAWS ch. 113, 14 (Law.Cop.Supp.1989); MICH. COMP. LAWS ANN. 333.10202 (1989); MISS. CODE ANN. 41-61-71 (Supp.1989); MO. ANN. STAT. 58.770 (Vernon 1989); MONT. CODE ANN. 72-17-215 (1989); N.C. GEN. STAT. 130A-391 (1989); N.D. CENT. CODE 23-06.2-04 (Supp.1989); OHIO REV.

states actively using the law)<sup>79</sup> operates in a shroud of secrecy; very few people are aware of these laws.<sup>80</sup> The second measure is found in the 1987 UAGA, containing a "reasonable effort to obtain consent"<sup>81</sup> provision, which closely resembles an "opt-out model."<sup>82</sup> Drafters of these provisions were hopeful that organ procurement would increase enough to meet a demand that, by the nineteen eighties (1980s), had grown exponentially.

In practice, however, the two provisions have been problematic and not the best solutions for increasing organ and tissue procurement.<sup>83</sup> According to Dr. Jim Martin, Executive Director of the Louisville Eye Bank in Kentucky, legislative consent was not successful in his state and annual deficits were experienced until they changed their procurement strategies and stopped operating under presumed consent.<sup>84</sup> Perhaps one reason for Kentucky's inability to meet demand under legislative consent was that the policy failed to garner the support of medical professionals and the eye bank community, and thus was not consistently or effectively applied.<sup>85</sup>

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CODE ANN. 2108.60 (Baldwin 1987); OKLA. STAT. ANN. tit. 63, 944.1 (West Supp.1990); R.I. GEN. LAWS 23-18.6-4 (1989); TENN. CODE ANN. 68-30-204 (Supp.1989); TEX. HEALTH & SAFETY CODE ANN. 693.012 (Vernon pamphlet 1990); UTAH CODE ANN. 26-4-23 (1989); WASH. REV. CODE ANN. 68.50.280 (Supp.1989); WIS. LAWS 157.06 (1989); W.VA. CODE 16-19-3a (1985).

<sup>79</sup>California, Florida, Hawaii, Kentucky, Louisiana, Maryland, Michigan, North Carolina, and Wisconsin.

<sup>80</sup>See Butgeriet, *Cornea Controversy*, *supra* note 40 (commenting that "Jefferson County [Alabama] isn't alone in wrestling over whether medical examiners should be allowed to remove corneas of dead people without their families' permission or knowledge"); Frammolino, *L.A. Coroner*, *supra* note 40 (citation omitted) (reporting that eye bank employees "say they were discouraged from seeking family permission so corneas could be harvested under state law").

<sup>81</sup>Jaffe, *supra* note 24, at 535-38.

<sup>82</sup>Opt-out models presume that a person is willing to consent to donation of her tissue unless she makes her wishes known to the contrary. *Id.* at 536 & n.36.

<sup>83</sup>Martin Interview, *supra* note 53; Larson Interview, *supra* note 53; Telephone interview with David Sierra, Hospital Development Technical Director for North Florida Lions Eye Bank (Feb. 23, 2000) [hereinafter Sierra Interview] (commenting that legislative consent "can't tell you what a person was doing at 4:00 am the morning prior"); Telephone interview with Kristen McCoy, Laboratory Director, Illinois Eye Bank, (Feb. 21, 2000) [hereinafter McCoy Interview] (commenting that they do not use the Illinois legislative consent statute because of a fear of law suits and ethical considerations).

<sup>84</sup>Martin Interview, *supra* note 53.

<sup>85</sup>*Id.*

In two interviews in Kentucky, and in subsequent conversations, Dr. Martin explained that the legislative consent policy was simply morally unacceptable and fraught with ethical and potential legal problems.<sup>86</sup> The problems ranged from quality of donor tissue to the possible overrepresentation of tissues harvested from young, poor black kids.<sup>87</sup> Therefore, the Kentucky medical community sought alternative solutions.<sup>88</sup> Other eye bank officials, including Mark Larson,<sup>89</sup> Donica Davis, Hospital Division Coordinator for the Tennessee Eye Bank, and Tom Buckley, Executive Director of The New England Eye and Tissue Transplant Bank,<sup>90</sup> complained about similar issues. At an interview in his Madison, Wisconsin office, Larson shared concerns quite similar to those addressed by Martin, including the idea that a sufficient supply "of transplantable corneas can only be obtained through effective hospital development and donor awareness programs"<sup>91</sup> and not through "shortcuts."<sup>92</sup> In an opinion paper, Larson indicates that experience with social history interviews with families of donors provides necessary information that is not required under the legislative consent policy.<sup>93</sup> Beyond the supply issue, consent, according to Larson, is simply "the right thing to do."<sup>94</sup>

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<sup>86</sup>*Id.* Dr. Martin suggested that Kentucky legislators adopted that states measure in response to the enactment of similar provisions by other state legislatures, and to strong lobbying efforts at both the state and federal levels by eye banks supporting legislative consent measures. *Id.* Ohio, Arkansas, and West Virginia, all border or region states with Kentucky, adopted similar statutes a year or two before Kentucky. *Compare* KY. REV. STAT. ANN. 311.187(1988); OHIO REV. CODE ANN. 2108.60 (1987); ARK. CODE ANN. 12-12-320 (1987); W.VA. CODE 16-19-3A (1985).

<sup>87</sup>Martin Interview, *supra* note 83.

<sup>88</sup>*Id.*

<sup>89</sup>Larson Interview, *supra* note 53 (stating that "not having consent is a bad thing. One bad thing can undue many things"); Telephone interview with Donica Davis, Hospital Development Coordinator, Tennessee Eye Bank, (Apr. 5, 2000) [hereinafter Davis Interview] (commenting that "we also want consent from the family"); Telephone interview with Tom Buckley, Executive Director of New England Eye and Tissue Transplant Bank (Apr. 6, 2000) [hereinafter Buckley Interview] (stating that, "philosophically, we have felt that, isn't it better to contact the families? for courtesy if nothing else?").

<sup>90</sup>Buckley Interview, *supra* note 89; Larson Interview, *supra* note 53; Davis Interview, *supra* note 89.

<sup>91</sup>Larson Interview, *supra* note 53.

<sup>92</sup>*Id.*

<sup>93</sup>Mark E. Larson, *Use of Tissue Recovered Using Medical Examiner/Coroner Laws* (Mar. 5, 1998) (unpublished manuscript, on file with the author.).

<sup>94</sup>*Id.*

Doyce Williams, however, is quick to point out that legislative consent "works" when done consistently. For example, the State of Alabama experienced annual surpluses in the supply of transplantable corneas until lawmakers abandoned legislative consent laws.<sup>95</sup> But can success be measured against a loss of community trust? Recent newspaper headlines in Alabama convey a much different attitude about legislative consent laws: "*Cornea Controversy: Eye Banks Don't See Eye To Eye*" and "*Mother Feels Corneas Were Stolen*."<sup>96</sup> These front-page news items illustrate the drama lurking behind consent laws that operate in a vacuum, without donor or relative consent, or any communication for that matter. These headlines came after investigative reports revealed that corneas were being harvested in Alabama, pursuant to state statute, without consent from the decedent's relatives. In a case that made headlines and resulted in an out-of-court settlement, a mother, Patsy Burton, learned about the medical examiner's removal of her teenage son's corneas only after reading news reports about the nonconsensual harvesting of tissues in Alabama.<sup>97</sup>

Angered at "not being given a chance" to give consent, Burton wondered, "what else can they do, or what do they do, when they have the chance?"<sup>98</sup> In a letter to the county commissioner, she asked, "did the coroner's office take my son's corneas because they were trying to help someone else see again or just because he was young and they thought nobody would care?"<sup>99</sup> According to Doyce Williams, the fallout from the negative publicity had a chilling affect on altruistic donations<sup>100</sup> and led to the abrupt abandonment of the legislative consent provision by lawmakers.<sup>101</sup>

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<sup>95</sup>Williams Interview, *supra* note 65. Mr. Williams proffered that more people had their vision restored under legislative consent laws, and they were able to export excess corneal tissue. However, the state has suffered a dramatic decrease in the amount of tissues available since the abandonment of legislative consent laws, the emergence of bad publicity, and lawsuits. *Id.*

<sup>96</sup>Butgereit, *Controversy*, *supra* note 40; Betsy Butgereit, *Mother Feels Corneas Were Stolen*, BIRMINGHAM NEWS (Alabama), Feb. 16, 1998, at A1 [hereinafter *Mother Feels*].

<sup>97</sup>See Butgereit, *Mother Feels*, *supra* note 96.

<sup>98</sup>*Id.*

<sup>99</sup>*Id.*

<sup>100</sup>Williams Interview, *supra* note 65 (commenting on the affect of negative publicity on cornea procurement).

<sup>101</sup>Karin Meadows, *Cornea Policy OK By Commissioners*, BIRMINGHAM NEWS

Thus, at what cost to community trust do such programs operate? In California, nonconsensual cornea harvesting caused community outrage and forced the Los Angeles County coroner's office to respond to the reports of "ethical breaches" by no longer "routinely permitting a local eye bank to harvest corneas without the permission or knowledge of surviving family members."<sup>102</sup> Accordingly, organ and tissue procurement should not be viewed as simply a numbers game.<sup>103</sup> Granted, saving lives, and restoring sight is important, but possibly at the cost of donor autonomy and community health.

Mary Jane O'Neil, a legislative consent proponent, notes that, "ten years ago people who would have been donors have been saved by seatbelt laws, helmet requirements, and gun control."<sup>104</sup> However, most Americans would probably agree that saving lives by restricting certain behaviors that are known to cause injury or even death is a "good thing to do,"<sup>105</sup> even if there are other Americans who would

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(Alabama), Feb. 19, 1998 at B1. (noting that "the matter became the subject of controversy after commissioners discovered the coroner's office wasn't obtaining permission to remove the dime-sized clear tissue for transplants"). After the series of news articles chronicling Patsy Burton's misfortune, the Jefferson County Commissioner's office now requires that the Alabama Eye Bank make efforts to contact the next of kin. *See Williams Interview, supra* note 53.

<sup>102</sup>Frammolino, *L.A. Coroner, supra* note 40 (citation omitted).

<sup>103</sup>*But see* Interview with Mary Jane O'Neil, Executive Director, Eye Bank Sight Restoration in New York, N.Y. (Feb. 21, 2000) [hereinafter O'Neil Interview]. Reconciling the need to restore sight and promote life by violating a dead body can be a clear-cut case for some. O'Neil lobbied for a medical examiner statute in New York, believing that it would increase the number of corneas available for transplantation, and that eventually "80% of people would care less." *Id.*

<sup>104</sup>*Id.* *See also* Fentiman, *supra* note 57, at 1594 n.6 (citing END STATE RENAL DISEASE FOUNDATION HEALTH CARE FINANCING RESEARCH REPORT (1990)) (commenting that "recent changes in both the law and public attitudes toward seat belt use and drinking and driving, along with broad demographic trends, have combined to decrease the pool of available donors").

<sup>105</sup>Erica Noonan, *Sprinkler Bill Stirs Some Debate*, BOSTON GLOBE, Feb. 25, 2001 at 3 (commenting that "safety prevention efforts save lives, noting its no different than saying it costs money to install seat belts and air bags and baby cars seats. . . . There are things we spend money on, and saving lives seems like a pretty good thing to spend money on"). *See also* Charles Wheelen, *Lives Changed In a Split Second*, N.Y. TIMES, Jan. 10, 2001, at A 19; Licia Corbella, *Don't Put Children Near Front Air Bags*, THE CALGARY SUN, Mar. 16, 2001, at 4; Lori Shontz, *Healing Rock: Process of Moving on after Earnhardt's Death Begins*, N.C., PITTSBURGH POST-GAZETTE, Feb. 25, 2001, at D1; Meredith Fischer and Will Jones, *Some Roads are Deadly: Deficient Design, Driver Inattention Can Be Fatal Mix*, RICHMOND TIMES DISPATCH (Virginia), at A1.

benefit from their corneas, kidneys, and other potential remains. Besides, the vision of a revolving door of people with poor behaviors dying only to supply their biological remains to those with less risky behaviors seems a bit macabre. Should only the safe-acting, less-risky-behaving be promised restoration of their vision or the gift of life? Should only those who are victims of others unsafe behaviors comprise the donor pool?

### *Religious Concerns*

Other ethical problems are posed by the legislative authorization to waive consent to autopsy and tissue harvesting. Certain cultural expectations and religious doctrines emphasize human dignity, the sacredness of the body, and preservation of life, even when medically the body may be considered "dead."<sup>106</sup> For example, Orthodox Judaism places a strong emphasis on life.<sup>107</sup> According to Elliot Dorff, a philosopher as well as a rabbi, Jewish law "requires that Jews take steps to preserve their life and health," even when secular law and medical practice might have determined death.<sup>108</sup>

Strong Judaic values associated with life pose difficulty for "agreeing to donate."<sup>109</sup> Moreover, the connection to the spiritual afterlife, and the belief in the existence after death of "spirits who look like the embodied people they were in life," is attributed to making the more conservative members of the Jewish faith reluctant to grant consent to donate.<sup>110</sup> It stands to reason, if a religious tenet, a belief in the sacredness of the body, and an uncertainty about when death occurs presently inhibit some Jews from voluntarily consenting to organ

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<sup>106</sup>Elliot N. Dorff, *Choosing Life: Aspects of Judaism Affecting Organ Transplantation*, IN ORGAN TRANSPLANTATION: MEANINGS AND REALITIES, *supra* note 31, at 168-93.

<sup>107</sup>*Id.* at 177. Elliot Dorff comments that, "from [his] own perspective, the value of saving lives ultimately overcomes objections to organ transplantation per se." *Id.* at 169. Dorff acknowledges, however, that organ donation is a complicated issue in Judaism because death is perceived as "extended over several phases, and [Judaism] has a basic diffidence with regard to our ability to define the moment of death exactly." *Id.* at 177. "Still," he writes, "deeply human factors shape our understanding of our bodies and of the divine image in which we are all created, and transplantation efforts must preserve the dignity and respect that God's creation demands." *Id.* at 169.

<sup>108</sup>*Id.* at 177.

<sup>109</sup>*Id.* at 177-78.

<sup>110</sup>*Id.* at 178.



donation, certainly a compulsory system, where no consent is required, would be considered offensive.<sup>111</sup> Indeed, Mary Jane O'Neil alluded to as much in an interview earlier this year.<sup>112</sup> According to O'Neil, "Jewish people would not donate and would fight [presumed consent]"<sup>113</sup> for the reasons suggested by Elliot Dorff and other commentators.

Proponents of legislative consent argue that those with religious objections can "opt-out" of consent, meaning that they can make known or register their refusal to donate.<sup>114</sup> Although opt-outs might be available, they are often more illusory than real.<sup>115</sup> First, many people are not aware of the existence of presumed or legislative consent policies.<sup>116</sup> Second, even if people were made aware of their rights, many are skeptical as to whether and how the opt-out provisions would be enforced.<sup>117</sup>

An extensive *Los Angeles Times* investigative report in which records from over 500 presumptive consent removal cases from a period in 1996 to 1997 were reviewed, suggests that most people are unaware that these laws exist.<sup>118</sup> The *Los Angeles Times* reporter handling the investigation interviewed numerous families who indicated their unawareness of the law, and were devastated to learn that their children, husbands, and daughters had their corneas removed

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<sup>111</sup>Mackenzie Carpenter, "Presumed" Donor Bill Aired, PITTSBURGH POST-GAZETTE, July 14, 1999, at A10 (raising questions about the constitutionality of proposed presumed consent measures because for "Native Americans, Orthodox Jews and most Asian religions, disemboweling the body is a sacrilege"); James Lindemann Nelson, *Transplantation Through A Glass Darkly*, 22 HASTINGS CENTER REP. No. 5, AT 6 (1992); ELLIOT PINSLEY, *Routine Donation of Organs Pushed; Ethics Group Seeks Presumed Consent*, THE RECORD, Dec. 22, 1992 at A1 (noting the fear among Orthodox Jews that presumed consent measures would be problematic and "that a government bureaucracy cannot be trusted to maintain proper records").

<sup>112</sup>O'Neil Interview, *supra* note 103.

<sup>113</sup>*Id.* O'Neil argued that the Jewish community organized and fought against legislative consent in New York and her organization, which lobbied to support a medical examiner statute, withdrew their proposal. *Id.*

<sup>114</sup>Pinsley, *supra* note 111 (commenting on James Nelson's presumed consent proposal, which "specified that people could opt not to have their organs removed if they objected on religious or philosophical grounds").

<sup>115</sup>See Frammolino, *Harvest of Corneas*, *supra* note 3.

<sup>116</sup>*Id.*

<sup>117</sup>See Frammolino, *L.A. Corner*, *supra* note 40.

<sup>118</sup>Frammolino, *Harvest of Corneas*, *supra* note 3.

without consent or the effort to obtain consent.<sup>119</sup> Two recent surveys conducted for this article revealed that over ninety percent (90%) of survey participants in states with limited consent laws are unaware that these laws exist.<sup>120</sup> One of the groups surveyed consisted of administrators in the Mayor's Office and members of the City Council of Lexington, Kentucky.<sup>121</sup> Only one of fifteen people surveyed in this group had heard about presumed consent, although Kentucky authorized the legislation over ten years ago.<sup>122</sup>

In addition to lack of awareness arises the question of whether opting out would work. Because timing is critically important to organ and tissue harvesting, the necessity to transplant in a timely manner might supercede waiting for a possible objection, particularly when the most viable tissues require harvesting within three to six hours after death. James Nelson's commentary on presumed consent and opt-out measures illuminates important ethical concerns:

A simple reliance on our moral intuitions isn't enough. As the history of medical research in the nineteenth and even twentieth century reveals, we have been more than will to subject those who were "clearly less valuable" to the rigors of research only then, the ones who were obviously less valuable were Jewish, or people of color. Our gut instincts simply aren't good enough as reliable moral guides when we're

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<sup>119</sup>*Id.*

<sup>120</sup>Michele Goodwin, *Organ Transplant Survey Analysis* (Feb. 16, 2000)(unpublished, on file with the author). The surveys were conducted over the phone in late January and February 2000. The author asked eleven questions of each participant. Of the initial one hundred surveys analyzed, the race groupings were eighty-six percent (86%) African American and fourteen percent (14%) White. Participants ranged in age from 18-70 years old. Sixty-five percent (65%) of the participants were 18-25 years old.

One survey was administered to 15 local government officials in Lexington, Kentucky, with the assistance of Janet Givens, special assistant to Mayor Pam Miller. The other survey was administered to one hundred participants through phone interviews. The participants were randomly selected from lists of names obtained from community leaders, clergy, college students, and community advocates. Participants were from Kentucky, Arkansas, Maryland, Alabama, Tennessee, and North Carolina.

Only one of the fifteen people (or 6.6%) surveyed in the Mayor's Office was aware of presumed consent laws in Kentucky. Of the larger group surveyed, only five of the one hundred people (5%) had ever heard of presumed consent laws.

<sup>121</sup>*Id.*

<sup>122</sup>*Id.* See also KY. REV. STAT. ANN. 311.187 (1988).

dealing with those whom we've pushed to the margin of moral discourse.<sup>123</sup>

*You Vang Yang v. Sturner*, the closest case on point, illustrates the difficulty with opting out of autopsies.<sup>124</sup> The Yangs, members of the Hmong community, adhere to the religious doctrines of the Hmongs, "one of which prohibits any mutilation of the body, including autopsies or the removal of organs during an autopsy."<sup>125</sup> The Yangs brought an action for damages after an autopsy was performed on their son, claiming that the Rhode Island autopsy statute, both facially and as applied by the medical examiner, violated their first amendment right to exercise their religion freely, and their fourteenth amendment rights to due process and equal protection.<sup>126</sup> The court held that the couple's exercise of religious beliefs against mutilation of a body was clearly established, and denied Sturner's qualified immunity defense. In reaching its decision for the plaintiffs, the court opined that a medical examiner should know the law governing his conduct.<sup>127</sup> Although the

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<sup>123</sup>Nelson, *supra* note 111, at 7-8 (proposing a presumed consent measure with opt-out provisions the same year his article was published).

<sup>124</sup>*You Vang Yang v. Sturner*, 728 F.Supp. 845 (D.R.I. 1990).

<sup>125</sup>*Id.* at 846.

<sup>126</sup>*Id.* at 847. The Yang's twenty-three-year-old son died from a seizure, but physicians involved with the case were unaware of what caused the seizure, and thus an autopsy was recommended and performed. *Id.* at 846.

<sup>127</sup>*Id.* at 853. *Yang* and its progeny are instructive on this point. The *Yang* trial judge felt compelled to reverse himself after the U.S. Supreme Court handed down its decision in *Employment Div., Dept of Human Res. of Oregon v. Smith*, 494 U.S. 872 (1990). *Yang v. Sturner*, 750 F. Supp. 558 (D.R.I. 1990).

In *Smith*, the Supreme Court held that "generally applicable, religion-neutral laws that have the effect of burdening a particular religious practice need not be justified by a compelling state interest." *Id.* at 887 n.3. However, under Congressional enactment of the Religious Freedom Restoration Act (RFRA) of 1993, 42 U.S.C. 2000bb et seq. (2000), state infringement or burden of religious exercise will be strictly scrutinized. States must demonstrate a compelling interest, and try to achieve that interest or goal through the least restrictive means. Indeed, the *Smith* case was criticized by members of Congress as having created an atmosphere in which unburdened expression of religious beliefs was jeopardized. See *Federal Document Clearing House Congressional Testimony*, June 23, 1999, CAPITOL HILL HEARING TESTIMONY, TESTIMONY JUNE 23, 1999 RUSSELL D. FEINGOLD SENATOR SENATE JUDICIARY PROTECTING RELIGIOUS LIBERTY (testifying about his discontent with the Supreme Courts Decision in *Smith*. "I voted for the original Religious Freedom Restoration Act (RFRA) in 1993 because I thought that the Supreme Court made a mistake in 1990 in the *Smith* case, in effect reducing the level of protection against government intrusion that religious expression in this country receives from the courts"). See also Mark Chaves and William Tsitos, *Are Congregations Constrained by Government? Empirical Results from the National*

court initially granted relief, there is some question about whether or not its actions would have been different were the autopsy performed and organs or tissue used for transplantation. Moreover, the case illustrates how one can find out too late to opt-out, at which point a legal victory may pale in comparison to the perception that a sons or daughter's soul is doomed to eternal unrest.<sup>128</sup>

### *Safety Concerns: Collecting Social Histories*

Several eye bank procurement officials cautioned about the quality of presumed consent tissue, noting that tissue and organs might not be "high quality" or "safe" because communicable diseases such as hepatitis B and C, rabies, and Creutzfeldt-Jakob syndrome (similar to mad cow disease) can be transmitted through corneas.<sup>129</sup> Their concerns arise from the loose, if any, health requirements of presumed consent donors. According to Mark Larson, presumed consent statutes do not mandate that social histories be obtained.<sup>130</sup> He states that social

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*Congregations Study*, 42 J. CHURCH & STATE 335 [hereinafter *Congregations Study*](quoting members of Congress disturbed by the Smith decision. Rep. Maloney from New York, for instance, stated that the fundamental right of all Americans to the free exercise of religion is in serious jeopardy. . . . "The Supreme Court's ruling in Smith has already begun to chip away at the first freedom protected by the Bill of Rights, the freedom of religion"). Representative Franks of New Jersey was also outspoken about the Smith decision. *Id.* Franks suggested that the implications of the Smith decision are especially burdensome for those whose beliefs lie within the religious minority. *Id.* But see *City of Boerne v. Flores*, 521 U.S. 507; 117 S. Ct. 2157 (1997) (holding RFRA unconstitutional and overly intrusive in states authority to regulate for the health and safety of its citizens and impinges upon principles necessary to further separation between church and state). Professor Drinan of Georgetown University Law School, however, suggests that the future is unclear if RFRA is not reinstated in some form. The problem is that no one will ever know. At the local level, zoning commissions will quietly deny access to Jewish temples, controversial denominations, or Catholic schools. See *Congregations Study*, *supra* note 127, at 335.

<sup>128</sup>Scholars also suggest that religious conflicts with presumed consent may have less to do with opposition to performing a loving and kind act that would benefit another, or even sharing human organs, but more to do with human dignity. The major obstacle is the perception of bodily harm or mutilation caused by the actual removal of organs. Philosophically, this view challenges the notion that a "dead body" is simply a corpse, no longer able to support feelings, emotions, thoughts, and therefore lacking a certain integrity or humanity that is deemed exclusively for the living. Rather, a profound respect for the deceased seems to drive religious doctrines that oppose compulsory organ harvesting.

<sup>129</sup>Larson Interview, *supra* note 53.

<sup>130</sup>*Id.*

history is usually provided through an interview with a family member or doctor.<sup>131</sup>

Larson explains that eye banks in Wisconsin do not recover tissue using the presumed consent legislation because "experience with next of kin [social] history interviews suggest that unique information is collected that is only available from this source."<sup>132</sup> The uniqueness of that information, he argues, allows him and his staff to make more appropriate determinations regarding issues of safety and suitability of tissue.<sup>133</sup> Accordingly, it would seem that increased collection of any donor information related to risk factors for infectious disease will reduce the risk of infectious disease transplantation.<sup>134</sup>

In most presumed consent cases, obtaining social histories presents certain obstacles. First, it requires communicating with survivors, who might opt-out of donating their relative's organs. Second, given the lifestyles of some presumed consent donors, they may not have survivors who can easily be contacted. Moreover, they may be part of a questionable health pool (drug users, have criminal histories, etc.). Frammolino's 1997 investigation of the Los Angeles coroner's office revealed that several pairs of corneas harvested for transplantation were from individuals who had been incarcerated (a donor pool considered not acceptable for transplantation by California's own eye bank community).<sup>135</sup> Furthermore, who does one contact to obtain the social history of a homicide victim with no driver's license? Presumed consent presents too many health unknowns.

Obtaining social histories may be somewhat antithetical to presumed consent procurement philosophy and strategies. As an Indiana official observed, "if you get their social history, you might as well obtain consent."<sup>136</sup> The purpose for these policies is to increase tissue procurement by avoiding consent obstacles, which the framers of the 1987 UAGA perceived as the significant problem in organ

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<sup>131</sup>*Id.*

<sup>132</sup>Larson, *supra* note 93, at 2.

<sup>133</sup>*Id.*

<sup>134</sup>*Id.*

<sup>135</sup>Frammolino, *Harvest of Corneas*, *supra* note 3.

<sup>136</sup>Telephone interview with Maurice Van Zance, Executive Director of the Indiana Eye Bank (Feb. 22, 2000) [hereinafter Van Zance Interview].

procurement.<sup>137</sup> Thus, according to Jim Martin, obtaining social histories, a policy that he supports, might be perceived as a self-defeating measure to presumed consent proponents.<sup>138</sup>

### *Overcoming Racial Perceptions*

Can an increased yield in biological materials justify the potential racial and socio-economic imbalances in the donor pools, particularly when those communities are less than likely to be recipients? Eye bank officials from Kentucky, Wisconsin, and Michigan expressed concern about the potential for an overrepresentation of young men of color to have homicide deaths before the coroner, and thus subject to mandatory autopsy or investigation.<sup>139</sup> Arguably, this would be a more relevant issue in urban communities where there are significant populations of people of color. However, Jim Martin of Kentucky suggested that such laws could also create disparities with racial impacts in smaller urban communities like Lexington and Louisville, Kentucky.<sup>140</sup>

Nonetheless, in New York, Los Angeles, Washington D.C., Baltimore, and Atlanta, presumed consent can have a devastating impact.<sup>141</sup> Presumed consent laws appear to be racially neutral on their face; in that way they do not target communities of color. However, as applied, they disproportionately affect people of color because blacks and latinos may be more likely to die by violent deaths (most homicides) than whites and most cases before medical examiners are homicides or violent deaths, followed by trauma-induced deaths.<sup>142</sup>

In a Los Angeles study, for example, seventy-two percent (72%) of the autopsies performed were on homicide victims. Accident victims, the next largest group, accounted for sixteen percent (16%).<sup>143</sup> The study also revealed that over eighty percent (80%) of those autopsied

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<sup>137</sup>Jaffe, *supra* note 24, at 532-37.

<sup>138</sup>Martin Interview, *supra* note 53.

<sup>139</sup>Martin Interview, *supra* note 53; Larson Interview *supra* note 53; Telephone interview with Florence Johnston, President & CEO, Midwest Eyebank (Apr. 6, 2000) [hereinafter Johnston Interview].

<sup>140</sup>Martin Interview, *supra* note 53.

<sup>141</sup>See, e.g., Frammolino, *Harvest of Corneas*, *supra* note 3.

<sup>142</sup>*Id.*

<sup>143</sup>*Id.*

(and who became involuntary tissue donors), were black and latino.<sup>144</sup> Only sixteen percent (16%) were white.<sup>145</sup> Thus, based on trends of death, gang violence, drug culture, and a host of other social problems that seem more concentrated in urban environments, it is not unforeseeable that legislative consent would disproportionately affect people of color, particularly youth and young adults. Frammolino, an investigative reporter for the *L.A. Times*, points out that the average age of those who legislatively "donated" was 27.7 years; according to his study, this is "much younger" than the average age of death.<sup>146</sup>

Given the potential for extreme racial disparities, legislative consent appears difficult to justify. Moreover, presumed consent would further exacerbate the distinct racial problems presently associated with organ allocation and transplantation.

#### PART IV. CAN PRESUMED CONSENT BE JUSTIFIED? COMMON LAW, DISTRIBUTIVE JUSTICE, & THE SOCIAL CONTRACT

*A pound of man's flesh, taken from a man, is not so estimable, profitable neither, as flesh of muttons, beefs, or goats.*<sup>147</sup>

*We give them a kinder, gentler death than they deserve to mark a boundary between the "civilised" and the "savage" ...*<sup>148</sup>

*The philosophies of law, and of medicine, are intimately bound to the mechanics of living, to preserving and enhancing our stake in the world. The issue of death remains peripheral to these processes.*<sup>149</sup>

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<sup>144</sup>*Id.*

<sup>145</sup>*Id.*

<sup>146</sup>*Id.*

<sup>147</sup> WILLIAM SHAKESPEARE, *THE MERCHANT OF VENICE* 18 (Yale University Press 1923) (1600).

<sup>148</sup>Austin Sarat, *Killing Me Softly: Capital Punishment and the Technologies for Taking Life*, in *COURTING DEATH*, *supra* note 1, at 69 (citation omitted).

<sup>149</sup>Melanie Williams, *The Sanctity of Death: Poetry and the Law and Ethics of*

Under what theoretical framework could a policy such as legislative consent be justified? It takes the form of a social and physical obligation, ostensibly for a community good. And what higher moral order could there be for a government than to support preserving and saving life? Ethically it is clear that saving lives is a worthy and noble humanitarian cause. Beyond being a "good cause," saving lives functions under the auspices of obligations born upon the state for the protection and safety of its communities. Indeed, why do governments exist at all, if not to preserve, promote, and defend a community's health and welfare?

Legislative consent is an example of a policy subsumed by mixed moral considerations and obligations. One obligation is for the state to preserve life and the health of its members. For this reason, Linda Fentiman proposed organ donation as a national service.<sup>150</sup> Another political obligation of a democratic society "is that the power of the state [be] circumscribed, even if what the state wants to do is a good thing."<sup>151</sup> Legislative consent creates a philosophical crossroad, where opposing interests must be weighed for ultimate action that will result in a justifiable and morally acceptable community benefit.

Politically and philosophically, presumed consent is perhaps best justified through the social contract. It demonstrates how we can live in what Rousseau referred to as the "chains" of civil society, while not compromising core values or principles, including freedom.<sup>152</sup> Through our relationships with the state are born obligations that are entered into involuntarily for the good of the common or whole.<sup>153</sup> Rousseau referred to these as general wills, in which the best interest of a group is considered collectively, rather than individually.<sup>154</sup> Why then would one choose to participate in the collective will if it means assuming a political, economic, or social burden?

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*Euthanasia*, in *COURTING DEATH*, *supra* note 1, at 88.

<sup>150</sup>Fentiman, *supra* note 34.

<sup>151</sup>Pinsley, *supra* note 111 (quoting ethicist Robert Royal).

<sup>152</sup>JEAN-JACQUES ROUSSEAU, *THE SOCIAL CONTRACT OR PRINCIPLES OF POLITICAL RIGHT* 5 (Wordsworth Classics 1998) (1762).

<sup>153</sup>*Id.*

<sup>154</sup>*Id.* at 14-16.



People want to engage in the general will (as Americans have done), when the exchange, or what is placed in return, affirms and protects values freedom, political autonomy, and free expression and customs. In this way the social contract is the operational and functional equivalent of insurance - an investment in preserving financial, social, and political order. However, the social contract works only if those involved believe themselves to be members of that society and the society in return grants them the benefits of membership and distributes goods equitably.<sup>155</sup> However, membership cannot be defined as simply physical placement. Slaves have historically been physically planted in foreign societies, but have lacked membership. The same is true of most foreigners; they are allowed physical space on foreign soil, however the benefits of a society are not always bestowed upon outsiders.

Does the social contract justify the use of present presumed consent laws? Could it support legislative consent for organ procurement?<sup>156</sup> As a moral justification to increase organ supply, by nonconsensually taking organs, the social contract ultimately does not work. Although social contract theory is perhaps the most persuasive moral justification for taking a good from another for the benefit of the whole, it cannot reconcile the disparities existing in the present system. Arguably, the social contract works only when applied equitably and distributive justice is achieved. Rousseau suggests that the basis for the entire social system is a society's membership becoming "equal by convention and legal right."<sup>157</sup>

Social compact theory ultimately fails to support the cause of presumed consent, particularly in the case of those with an "othered" or "outsider" existence.<sup>158</sup> Arguably, for America's disenfranchised

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<sup>155</sup>*Id.* at 15. Rousseau reduced the notion of the social contract to the idea that "each of us puts in common his person and his whole power under the supreme direction of the general will; and in return we receive every member as an indivisible part of the whole." *Id.*

<sup>156</sup>See Anderson, *supra* note 65, at 262-68.

<sup>157</sup>ROUSSEAU, *supra* note 152, at 23.

<sup>158</sup>See CHARLES W. MILLS, *THE RACIAL CONTRACT* (1997); Robin D.G. Kelley, *Playing for Keeps: Pleasure and Profit on the Postindustrial Playground, in THE HOUSE THAT RACE BUILT 195* (Wahneema Lubiano, ed. 1997) (arguing that America has a racial contract, which leaves blacks out and causes their exploitation).

members, the social compact lacks legitimacy.<sup>159</sup> The existence of a social compact naturally depends on a demonstrable social contract, where allocation is equitable and proportionate to resources derived from a particular community. To this end, social compacts between the disenfranchised with an "othered" American experience and the greater community are legitimate only to the extent that the marginalized groups have equitable access to and distribution of the goods claimed by the larger community.

### Jurisprudential Analysis of Dead Bodies and the State

*Jurisprudents observe that the legal order asserts that people are obligated, not just obliged to obey the law.*<sup>160</sup>

Legal order, at least from a jurisprudential perspective, tends to suggest an intimate, although perhaps not always desired association between the community, property and the law.<sup>161</sup> Quasi-mandatory obligations and responsibilities measure this relationship. In one's acquiescence to the law is found a community good that becomes realized. At its liberal utilitarian core, jurisprudential analysis reminds us that rights to a particular "thing" are always conditioned upon governmental necessity.<sup>162</sup> Accordingly, Andrew Beckerman-Rodau suggests the purpose of this condition is to preserve the safety and health of the greater populace.<sup>163</sup>

In this basic concept, proponents of presumed consent justify the nonconsensual appropriation of organs.<sup>164</sup> However, their proposals

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<sup>159</sup> See MILLS, *supra* note 158; Kelly, *supra* note 158.

<sup>160</sup> C. Edwin Baker, *The Media That Citizens Need*, 147 U. PA. L. REV. 317, 327 (1998).

<sup>161</sup> *Id.*

<sup>162</sup> *Id.*

<sup>163</sup> Andrew Beckerman-Rodau, *Are Ideas Within the Traditional Definition of Property? A Jurisprudential Analysis*, 47 ARK. L. REV. 603, 607 (1994). *But see* Brotherton v. Cleveland, 923 F.2d 477, 481, 482 (6th Cir. 1991) (holding that "the only governmental interest enhanced by the removal of the corneas is the interest in implementing the organ/tissue donation program; this interest is not substantial enough to allow the state to consciously disregard those property rights which it has granted").

<sup>164</sup> Fentiman, *supra* note 34; Jesse Dukeminier, Jr., *Supplying Organs for Transplantation*, 68 MICH. L. REV. 811 (1970); Theodore Silver, *The Case for a Post-Mortem*

disproportionately require something intimate and irreplaceable from those most vulnerable because of their unchangeable social and cultural status within the United States. As suggested earlier, those more likely to be the donors under a traditional presumed consent law are people of color and the urban poor.<sup>165</sup> While it is a laudable goal that Americans share organs to improve the quality of life for others, placing the onus of such policies on the most vulnerable, rather than the most capable, seems inequitable and reminiscent of slavery.<sup>166</sup>

Rousseau characterizes slavery as the function of one (or a community) alienating herself (or itself) by gift or sale. In the case of sales, one obligates herself in exchange for means of support.<sup>167</sup> However, the gift scenario is absurd and "inconceivable" according to Rousseau.<sup>168</sup> Why would any group give itself for nothing? Accordingly, Rousseau argues the inconceivability of minority or disenfranchised communities voluntarily alienating themselves for non-reciprocated benefits bestowed upon those with greater social status. Moreover, Rousseau likens forced or involuntary servitude disproportionately affecting those with minority status to a socially unconscionable practice that resembles social madness.<sup>169</sup> Social policies that unfairly burden a particular group are unjust at their very core.

### *State Ownership of Bodies?*

Consider, for example, that lawmakers do not require the wealthy to share wealth in order to eliminate poverty. While it is true that estate taxes help to fund programs that benefit the general population, sometimes those benefits are kept close to home (e.g., schools, quality of streets, policing, etc.). Consider a social policy of alleviating poverty. Recently, commentators have proposed that sound transportation policies could help poor mothers who cannot commute to work.<sup>170</sup>

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*Organ Draft and a Proposed Model Organ Draft Act*, 68 B.U. L. REV. 681 (1988).

<sup>165</sup>See, e.g., Frammolino, *Harvest of Corneas*, *supra* note 3.

<sup>166</sup>See ROUSSEAU, *supra* note 152, at 9-13.

<sup>167</sup>*Id.* at 9.

<sup>168</sup>*Id.*

<sup>169</sup>*Id.*

<sup>170</sup>See, e.g., Catherine Blake, *Survey To Deal With Transportation Needs*, L.A. TIMES, Mar. 9, 2000, at 3; Jean Hopfensperger, *Study Offers A Hand on Welfare-To-Work*, STAR

Such policies could include providing cars to these women.<sup>171</sup> If poverty and homelessness could be eliminated, or at least alleviated, by individuals having the ability to obtain jobs and commute to work, wouldn't that be a good social cause?

However, the state does not mandate that individuals with more than five cars provide one to a capable but "transportationless" individual so that she might attend school, go to work, participate in a training program, or pick up her children from childcare. Having five cars seems a bit excessive; after all, how many cars does one need? Clearly, automobiles are not needed after death. Thus, although the cars could be left to a deceased person's family, would they need them? It is not inconceivable that one of the best social uses for multiple cars from an estate would be to provide one to the state for a campaign to eliminate poverty.

Would we dare shape a proposal that requires those who die with five cars to leave one to the state as part of an anti-poverty program? Probably not, although sharing one of five cars is clearly not as invasive when compared with removing one's organs for transplantation into a stranger. If an anti-poverty car policy worked as clandestinely as presumed consent presently does, the policy might seem all the more outrageous. The wealthy, who would likely be disproportionately affected by this plan, might charge that it is unfair to those who earned their cars through hard work. Why, they might persuasively argue, should the burden of helping the underclass be disproportionately borne by them?

One could extrapolate and apply the same reasoning to the dead. At one's death the State does not transfer one's property to a stranger simply because it might benefit the person receiving the property.

In theory, life tenancy in human flesh, while troubling, is nonetheless thought provoking. If Americans participated in a new social program, which allowed the State to use their bodies as needed at death, perhaps more transplants would occur.<sup>172</sup> The plan could occur with limited restrictions placed on the donor during life, thereby

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TRIBUNE, Mar. 17, 2000, at 1A.

<sup>171</sup>See Pat Harper, *Savoring A Role in Workplace*, CHI. TRIB., May 11, 1999, at 3; Blake, *supra* note 170; Hopfensperger, *supra* note 170.

<sup>172</sup>Fentiman, *supra* note 57.

causing minimal interference in lifestyle, and the donor could perform the ultimate form of community service.<sup>173</sup> Arguably, this type of service to the State is less invasive and risky than military service,<sup>174</sup> or even jury duty. Indeed, in other capacities service to the State may alter one's lifestyle through injury, for example, and emotional and physical health could become an issue. Hence, proponents like Fentiman and Dukeminier conclude that presumed consent at one's death allows one to serve the State while, unlike in military service, not being burdened with the obligation during life.<sup>175</sup>

Nevertheless, there is something eerie about the State's involvement with body ownership. America's precedent with treating the body as property, slavery, surely demonstrates the absurdity of community ownership in the body or the ownership of anyone other than the possessor embodying the flesh. While it might be equally eerie to think of self-ownership from the grave, somehow that seems less unconscionable than the state partaking in ownership, use, and possibly research activities with corpses.<sup>176</sup>

Ironically, theories of tenancies in the flesh with some reversion to the community were not applied to slaves, as their masters or *owners* were protected and respected within the context of the law as propertied persons.<sup>177</sup> Mills argues that slavery, as a form of ownership of another, was justified under an unnamed social and economic policy to which he refers as the "slavery contract."<sup>178</sup> Basic principles of property jurisprudence make clear that owned possessions are under the exclusive direction of the owner.<sup>179</sup> To illustrate, although the institution of slavery provided a collective benefit to the growth and development of America, slaves were not on loan to their masters for a

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<sup>173</sup>*Id.* at 1598.

<sup>174</sup>*Id.* at 1600.

<sup>175</sup>Fentiman, *supra* note 57; Dukeminier, *supra* note 164. See also Silver, *supra* note 164.

<sup>176</sup>See Scott, *infra* note 245, at 27 (commenting on Western slavery starting in 10A.D. 1066 when the Normans conquered the Anglo-Saxons who had a "fully developed, legally regulated system of slavery." Slavery would not disappear in the West until the nineteenth century).

<sup>177</sup>See MILLS, *supra* note 158, at 24-25.

<sup>178</sup>*Id.* at 24.

<sup>179</sup>See ROUSSEAU, *supra* note 152, at 21.

life tenancy, with reversion to the greater community at their deaths.<sup>180</sup> Because slavery was a financial as well as a social institution, its success depended on maximizing the use of its workforce (property). Thus, any appropriation of the enslaved, either during or after the slave's life, would have required compensation from the appropriator to the owner.<sup>181</sup>

An historical examination of the law's engagement with the body more accurately demonstrates the community's distance from the body at death. In fact, the law's only interaction with the body at death was to order its speedy and sanitary burial.<sup>182</sup> Despite its incoherence, the common law as related to corpses demonstrates more clearly a protection of the community from outrage and nuisance, rather than protecting or recognizing a community ownership of the dead. A review of the legal history illumines the status of the body at death.

### *Dead Bodies & The Courts*

To hurl a dead body into a river, to cremate a dead body in a manner which might cause a public nuisance, and to mutilate a dead body were all offenses at common law.<sup>183</sup> At common law, the state's interest in the disposal of dead bodies was premised on concerns for public health

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<sup>180</sup>See ROBERT WILLIAM FOGEL & STANLEY L. ENGERMAN, *TIME ON THE CROSS: THE ECONOMICS OF AMERICAN NEGRO SLAVERY* (1974); JOHN W. BLASSINGAME, *THE SLAVE COMMUNITY: PLANTATION LIFE IN THE ANTEBELLUM SOUTH* (1972)(critiquing slavery in the American South).

<sup>181</sup>FOGEL & ENGERMAN, *supra* note 180.

<sup>182</sup>*Travelers Ins. Co. v. Welch*, 82 F.2d 799 (1936); *O'Donnell v. Slack*, 55 Pac. Rep. 906, 907 (1899) (opining that "the duty of the burial of the dead is made an express legal obligation").

<sup>183</sup>*State v. Bradbury*, 9 A.2d 657 (Me. 1939). In *Bradbury*, the defendant was convicted for the common law offense of burning a body in an indecent manner that would evoke public outrage and disgust. To expedite the disposal of his sister's body, the defendant built a hot fire in his basement furnace, bound the legs of his dead sister, and dragged her to the cellar, where he shoved her into the burning stove. The court emphasized that such activity caused a "heavy dark smoke" with a disagreeable odor to pour from the house. Holding the defendant guilty of improper disposal of a corpse, the court noted that the brother's actions toward the corpse were reprehensible and void of any decency expected of civilized people. *Id.*

and decency.<sup>184</sup> Thus, any disposal of a dead body that was contrary to common decency was considered a criminal offense.<sup>185</sup>

Traditionally, the right to bury or otherwise dispose of the dead belonged to the decedent's next of kin.<sup>186</sup> This possessory interest was considered a "quasi property" right by most courts.<sup>187</sup> Until the nineteenth century, a person had no power to direct the disposition of her body at death.<sup>188</sup> Courts recognized the burial duties of the next of kin for two reasons. First, public health and safety required the speedy burial of dead bodies. This goal was achieved with relatively low transaction costs because relatives already had possession of the body. Moreover, the state bore minimal enforcement expenses because relatives had an emotional stake in expediting the burial or disposition of the corpse.<sup>189</sup>

Second, it was assumed that the decedent's next of kin would benefit from the decedent's estate; therefore, it was expected that some of that benefit should or would be appropriated to pay for burial expenses. Burial rationales premised on public health and decency led to the establishment by the common law courts of limited property rights in the dead recognizing the next of kin as the proper party to dispose of relative's bodies.<sup>190</sup> Courts made clear that while such rights

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<sup>184</sup>See, e.g., Nicolas P. Terry, *Alas! Poor Yorick, I Knew Him Ex Utero: The Regulation of Embryo and Fetal Experimentation and Disposal in England and the United States*, 39 VAND. L. REV. 419, 426 (1986).

<sup>185</sup>*Id.*

<sup>186</sup>*Spiegel v. Evergreen Cemetery Co.*, 186 A. 585, 586 (N.J. 1936); Jaffe, *supra* note 24, at 543. Jaffe notes:

The current rule at common law is that the next of kin have the right to possess the dead body for the purposes of burial or other disposition. The right is typically characterized as one for possession of the cadaver, in undisturbed condition, and gives rise to actions such as wrongful autopsy and wrongful possession of the body.

*Id.* (footnote omitted).

<sup>187</sup>*Brotherton v. Cleveland*, 923 F.2d 477, 481 (6th Cir. 1991) (citing *Spiegel*, 186 A. at 585); *In re Estate of Moyer*, 577 P.2d 108, 110 n.5 (Utah 1978); *Arnaud v. Odom*, 870 F.2d 304, 308 (5th Cir. 1989) ("Louisiana has indeed established a 'quasi-property' right of survivors in the remains of their deceased relatives."); *Fuller v. Marx*, 724 F.2d 717, 719 (8th Cir. 1984) ("Under Arkansas law, the next of kin does have a quasi-property right in a dead body") (citation omitted).

<sup>188</sup>See Dukeminier, *supra* note 164.

<sup>189</sup>*Id.*

<sup>190</sup>*Brotherton*, 923 F.2d at 480-81.

are not absolute in the full proprietary sense (*i.e.*, owning the body), property rights nevertheless exist in the flesh for purposes of corpse disposition and are protected by the courts.<sup>191</sup> Most courts refer to this right as one of "quasi property." With the recognition of this property interest, relatives aggrieved by the mishandling or mutilation of the corpse are entitled to legal redress.<sup>192</sup>

However, the burial statutes, which recognize or vest a property interest in the next of kin, provide a limited possessory right. For example, a relative cannot choose to sell the corpse of her deceased relative, although she might be able to sell her hair, nails, and other body parts. Other rights, as Jaffe points out, "are excluded from the common-law formulation" of quasi property rights in the dead.<sup>193</sup> Indeed, this right does not exist during the decedents life, it cannot be conveyed, has no pecuniary value, and carries the liability for disposition.<sup>194</sup> Prosser and Keeton characterize the nature of claims related to property interest in dead bodies as "something evolved out of thin air to meet the occasion, and that in reality the personal feelings of the survivors are being protected, under a fiction likely to deceive no one but a lawyer."<sup>195</sup>

However, as law and technology have evolved in the area of the genetics, for example, individuals may now claim interest in the disposal of their own bodies. This right has not always been clear. In fact, some courts have recognized it as a limited right, noting that "laws

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<sup>191</sup>*Id.* But see *Doodeward v. Spence*, 6 C.L.R. 406 (Austl. 1908) (holding that possessory interests vesting in the next-of-kin were not limited to burial). In *Doodeward*, the High Court of Australia determined that a mother had a possessory right in the corpse of her two-headed, still-born child. Forty years after the child's birth in New Zealand the mother discovered that the corpse had been preserved by the physician and later sold to a carnival owner, who charged an admission fee for the public to view the body. The court upheld the plaintiff's cause of action in conversion and detinue, holding that the law did not forbid the possession of a human body for purposes other than burial.

<sup>192</sup>See, e.g., *Brotherton v. Cleveland*, 923 F.2d 477 (6th Cir. 1991); *Crocker v. Pleasant*, No. SC95148, 2001 Fla. LEXIS 151; 26 FLA. L. WEEKLY S61, Feb. 1, 2001 (clarifying that Florida recognizes a limited right to possession of the body of a loved one for burial which constitutes a legitimate claim of entitlement or quasi-property interest entitled to procedural due process protection under the Constitution).

<sup>193</sup>Jaffe, *supra* note 24, at 543.

<sup>194</sup>W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS 12, at 63 (5th ed. 1984).

<sup>195</sup>*Id.*



relating to wills and the descent of property were not intended to relate to the body of a deceased."<sup>196</sup> However, some of the common law limitations have been lifted by subsequent statute, thereby creating and granting the decedent herself first interest of corpse disposition.<sup>197</sup>

Decisions dealing with property rights in dead bodies were first rendered in English courts. Justice Martin in *Brotherton* observed that the "English common law held that there was no property right in a dead body, and therefore, it could not be disposed of by will."<sup>198</sup> Such decisions have been criticized by legal scholars, "noting that the primary reason for the rule was the historical anomaly that all matters concerning dead bodies were under the jurisdiction of the ecclesiastical courts, and thus, were not subject to common-law analysis."<sup>199</sup> Early American courts had mixed interpretations of claims involving dead bodies; some adopted the English common-law rule, while others "held that the rule was unsound" given the evident nature of rights bestowed upon relatives to possess and dispose of the decedents.<sup>200</sup> It is now the prevailing rule in England and the United States that there exists at least a "quasi property interest" in dead bodies. The recognition of those rights should, and naturally does, correlate with advancements in technology, biotechnology, and medical advancements.

Most judges, scholars, and commentators agree that statutory intervention became necessary to increase organ donation.<sup>201</sup> As public awareness grew regarding organ donation, more individuals desired to participate in the process. However, this posed a problem for doctors confronted with relatives refusing to relinquish disposition rights of the corpse. The 1968 and 1987.<sup>202</sup> UAGAs thus served to eliminate the tension surrounding burial rights, allowing individuals to determine the disposition of their bodies prior to their deaths.<sup>203</sup>

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<sup>196</sup>In re Estate of Moyer, 577 P.2d 108, 110 (Utah 1978).

<sup>197</sup>See Uniform Anatomical Gift Act (1987).

<sup>198</sup>*Brotherton*, 923 F.2d at 481 (citation omitted).

<sup>199</sup>*Id.* (citation omitted).

<sup>200</sup>*Id.*

<sup>201</sup>*Lyon v. United States*, 843 F. Supp. 531 (D. Minn. 1994); *Ramirez v. Health Partners of S. Ariz.*, 972 P.2d 658 (Ariz. App. Div. 2 1998); *Anderson*, *supra* note 65; *Coleman*, *supra* note 76; *Jaffe*, *supra* note 24.

<sup>202</sup>UAGA 1987 2.

<sup>203</sup>See *Moyer*, 577 P.2d at 110 (holding that a person has a property interest in his body). The Supreme Court of Utah upheld the decedent's right to determine the post-mortem

In fact, courts have interpreted the UAGA to support an individual's possessory rights and property interest in her body, even in death. The Utah Supreme Court relied on the state's adoption of the UAGA in the case of *In re Moyer*.<sup>204</sup> In that case, the decedent's mother disregarded his disposition plans, having his body buried instead of cremated as per his request.<sup>205</sup> The decedent's representative obtained a court order to exhume and cremate the body according to the original request of the decedent. On the mother's appeal, the Utah Supreme Court upheld the lower court order, holding that the decedent had a property right of a special nature in determining "the disposition of his body after death."<sup>206</sup>

The law has not generally provided for the reversion of corpses back to the community through either statute or common law Native American treaty resolutions and developments as ideal, though on quick inspection several cases seem to point in that direction.<sup>207</sup> However, certain cases involving hospital misappropriation and nonconsensual removal of body materials have turned on whether such actions occurred in good faith. Both the *Ramirez* and *Lyon* cases discussed earlier are instructive on this point. In both cases, summary judgment was granted based on the conclusion that the defendant hospitals acted in good faith when arranging to have decedent's body parts removed. In both cases, the families signed forms that were

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disposition of his body. *Id.*

<sup>204</sup>*Id.* at 110 n.4.

<sup>205</sup>*Id.*

<sup>206</sup>*Id.* at 110.

<sup>207</sup>*See, e.g.,* State v. Powell, 497 So. 2d 1188 (Fla. 1986). *See also* Georgia Lions Eye Bank v. Lavant, 335 S.E. 2d 127 (Ga. 1985). In *Georgia Lions*, parents of an accident victim filed suit against an eye bank that was authorized by the state medical examiner to remove their son's corneas. The parents were not consulted and did not authorized the removal. The trial court held in favor of the parents, finding that the imposed consent statute violates due process in that it deprives a person of a property right in the corpse of her next of kin, and fails to provide notice and an opportunity to object. The Georgia Supreme Court reversed, holding that there is no constitutionally protected right in a decedent's body. *Id.* at 128. The majority rationalized the concept of "quasi-property" rights to be a mere regulation which promotes public health and safety. The court further held that whatever quasiproperty right existed was not of constitutional dimension. *Id.* at 129. However, Justice Marshall's dissent noted that the statute failed to provide notice to the next-of-kin and a realistic opportunity to object to the organ removal, thereby fundamentally denying due process. *Id.* (Marshall, J., dissenting). *See also* Tillman v. Detroit Receiving Hosp., 360 N.W.2d 275 (Mich. Ct. App. 1984).

misread and subsequently miscommunicated to procurement agencies that removed tissues or bones without the families' consent. Both families filed suit upon learning that hospital staff had miscommunicated their intent, and thereby permitted the removal of their children's tissues.

The reasoning of both courts focused on the confusion resulting from miscommunicated or mistaken consent. The courts distinguished the claims regarding mishandling of dead persons based in mere negligence from those involving intent. The *Ramirez* court was clear in distinguishing its decision, based on "mistaken communication" done in good faith (and thereby recognizing the hospital's qualified immunity), from the decision in *Perry*, a case involving a nurse engaged in "intentional wrongdoing," who demonstrated "more than a mere mistake, bad judgment, or understandable confusion" when coercing a family to donate tissues of its decedent.<sup>208</sup> The Court concluded that, "as the *Perry* case illustrates, claimants who have been injured by bad faith actions of person involved in the organ donation process may sue and recover against them."<sup>209</sup> Nevertheless, one might conclude, perhaps accurately, that the *Ramirez* court, along with others, supports the notion that ultimately the State's interest in saving lives outweighs individual or family disposition requests.<sup>210</sup>

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<sup>208</sup>*Ramirez*, 972 P.2d at 667 (distinguishing *Perry v. St. Francis Hosp. and Med. Ctr.*, 886 F. Supp. 1551 (D. Kan. 1995)).

<sup>209</sup>*Id.*

<sup>210</sup>The Court notes that organ donation is "often referred to as the 'gift of life,'" and observes that, even as a "recent medical phenomenon" it saves lives and has "tremendous benefits for mankind." *Id.* The Court went on to state that "even if qualified immunity were not provided by statute, the foregoing policy considerations militate in favor of such protection and influence our crafting of common law liability rules in this area." *Id.*

The *Ramirez* court also distinguished that case from previous cases involving the mishandling of dead bodies. *Id.* at 665. In prior successful plaintiff decisions, the Court noted, organ donation was not at issue, pointing to perhaps a future of common law decisions where claims involving organ donation are weighed differently. Previous Arizona courts that addressed the issue relied on the Restatement 868, which provides in part: "One who intentionally, recklessly or negligently removes, withholds, mutilates or operates upon the body of a dead person or prevents its proper interment or cremation is subject to liability to a member of the family of the deceased who is entitled to the disposition of the body." *Id.* (citing RESTATEMENT (SECOND) OF TORTS 868 (1979)). While the RESTATEMENT would appear to fit squarely into an analysis based on negligence, the Court provided several loosely guided reasons against doing so in this particular case. The *Ramirez* family, relying on two prior Appellate Court decisions invoking the RESTATEMENT, was undoubtedly surprised by the

Consider also that some Courts recognize the nonconsensual appropriation of body parts from cadavers as cognizable claims under 42 U.S.C. section 1983. In those cases, the courts recognize that the next of kin have been deprived a right secured by the Constitution or laws of the United States, and that the deprivation occurred under color of law.<sup>211</sup> To assert a valid due process claim, a plaintiff must successfully demonstrate (1) a deprivation, (2) of property, (3) under color of state law.<sup>212</sup> The *Brotherton v. Cleveland* court, sitting in a presumed consent jurisdiction, found that those elements were met in a widow's civil action arising out of the county coroner's violation of equal protection and due process rights in authorizing the procurement and donation of her husband's corneas without her consent. Although the lower court dismissed the action for failure to state a claim, the Court of Appeals held that the widow had a legitimate interest and claim of entitlement in her husband's body (including his corneas) protected by the due process clause, and that the procurement was caused by established state procedures requiring a "predeprivation" process.<sup>213</sup> The Court reasoned that "the importance of establishing rights in a dead bodies has been, and will continue to be, magnified by scientific advancements," noting that the human body is a "valuable resource."<sup>214</sup> Judge Martin concluded that it was not inconceivable that in the future kidneys, hearts, and other organs could be maintained outside of the body, alluding also to the capacity to cultivate the resources in a dead body.<sup>215</sup>

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Courts reasoning: "that we followed 868 for claims of wrongful disinterment, burial, and disposal of a decedent's remains does not necessarily mean that we should do so in this case."

*Id.*

<sup>211</sup> *Brotherton v. Cleveland*, 923 F.2d 477, 479 (6th Cir. 1991).

<sup>212</sup> *Id.* at 479. Note also, the *Brotherton* Courts observations:

[T]hese three elements are necessary to establish a violation of due process under the fourteenth amendment; however, they alone are insufficient. She must also show either (1) the conduct was caused by "established state procedure rather than random and unauthorized action," . . . or (2) the means of redress for property deprivations provided by the state of Ohio fail to satisfy the requirements of procedural due process.

*Id.* (citations omitted).

<sup>213</sup> *Id.* at 477.

<sup>214</sup> *Id.* at 481.

<sup>215</sup> *Id.*

Nevertheless, it has become clearer over time that one is in full possession and in some ownership of herself, at least in life, and perhaps also in death.<sup>216</sup> *Moore v. Regents of the University of California* case struggles with this idea, but quite clearly concludes that "for better or worse, we have irretrievably entered an age that requires examination of our understanding of legal right and relationships in the human body and the human cell."<sup>217</sup> In *Moore*, the plaintiff suffered from hairy cell leukemia and underwent a spleen-removal operation at the UCLA Medical Center. After the operation, and without the plaintiff's consent, doctors used the spleen to produce a cell line, which they later patented. Upon discovering this, Moore sued the doctors for conversion. Although his conversion claim on appeal ultimately failed, the court nevertheless recognized a possessory interest held in one's body, holding that the rights of dominion are so similar to property interests "that it would be subterfuge to call them something else."<sup>218</sup> The subsequent tension in *Moore* regarding the conversion claim, could perhaps best be characterized by the Court's reticence to open a potential floodgate of litigation by extending the tort of conversion in that particular context along with considerations about the benefits of medical research.<sup>219</sup> If perhaps adjudicated today, the ultimate holding in *Moore* might be significantly different. While state action may limit this right or limit certain activities (*e.g.*, organ selling, prostitution, and sodomy) in which one may engage with respect to her body, it nonetheless vests the individual with broad authority to treat her body as she wishes during and after life. Moreover, it rests post-mortem disposition of the corpse with the individual or her family rather than the State.

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<sup>216</sup>Jefferies, *supra* note 26, at 627. Jefferies notes: "With human materials, people certainly own them, but lack the stick which encompasses the right to sell." *Id.*

<sup>217</sup>*Moore v. Regents of the University of California*, 249 Cal. Rptr. 494, 504 (Ct. App. 1988).

<sup>218</sup>*Id.* at 505. *But see also*, *Moore v. Regents of Univ. of California*, 51 Cal. 3d 120 (1990) (clarifying that plaintiff had no ownership interest in his cells after they left his body, however opining that Moore did state a claim for breach of physicians disclosure of obligations).

<sup>219</sup>*Moore v. Regents of Univ. of California*, 51 Cal. 3d 120, 136 (1990) (noting that "we consider . . . whether it is advisable to extend the tort to this context").

### The Body & Social Contract Theory

*There does appear, however, to be a cultural impediment to personification of the corpse. The reason is that personification of the body, alive or dead, would seem to demand the embodiment of the person, but this is not the Western way of thinking of persons who are conceived of, instead, as abstract will. We might even say that the Western legal person is a brain (really a mind) on a stalk.<sup>220</sup>*

Presumed consent is perhaps best justified through the social contract.<sup>221</sup> Viewed through a collective scheme of social justice, the procurement and allocation of scarce organs is a worthy social goal.<sup>222</sup> In various ways our national healthcare system has demonstrated a commitment to promoting health and safety, and provides a safety net for the very poor through Medicaid and Medicare. This distribution is to address present health needs through societal obligation, and helps to correct past inequities that unfairly burden the disenfranchised and limit their opportunities.

Although philosophers and scholars, among them Rousseau, Rawls, Hobbes, and Locke, who carved out early thinking on social obligations, duties, and responsibilities for the nation State are not commonly invoked in judicial opinions considering presumed consent,

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<sup>220</sup>Ngairé Naffine, *'But a Lump of Earth?': The Legal Status of the Corpse*, in *COURTING DEATH*, *supra* note 1, at 106 (1999).

<sup>221</sup>For an overview of social contract theory, see ROUSSEAU, *supra* note 148; Ernest Barker, *INTRODUCTION TO SOCIAL CONTRACT: ESSAYS BY LOCKE, HUME, AND ROUSSEAU* (1947); JOHN RAWLS, *A THEORY OF JUSTICE* (1971); MICHAEL LESSNOFF, *SOCIAL CONTRACT* (1986); Will Kymlicka, *The Social Contract Tradition*, in *A COMPANION TO ETHICS* (1991); Jean Hampton, *Contract and Content*, in *A COMPANION TO CONTEMPORARY POLITICAL PHILOSOPHY* (Goodin & Pettit eds., 1993).

Other justifications for presumed consent can be made, including: (a) presumed consent avoids families having to be approached about organ donation--and the negative consequences possibly experienced by grieving family members who now must be asked for authorization; (b) presumed consents are real, not illusory consents. One truly has a choice of whether to donate. The opt-out provisions provide protections for the potential donor and her family who may decide to change their minds.

<sup>222</sup>Fentiman, *supra* note 57.

their philosophical child, social contractual theory, is not as removed. Indeed, social compact theory may be the strongest argument for presumed consent. While the quality, or perhaps the potential outcome for the argument does not rise to the level necessary to justify its prophylactic implementation, since it limits individual autonomy and removes donor consent (at least in my opinion), it is nonetheless worthy of consideration in this article.

Ideally, presumed consent promotes the equitable distribution of scarce resources. As with other organ procurement schemes, it poses moral and ethical challenges.<sup>223</sup> Fentiman, Dukeminier, and Nelson argue, however, that these moral challenges are largely overcome by the tremendous social good that is done.<sup>224</sup> Annually, over 69,000 people await new organs.<sup>225</sup> Some will die before a donor is found. Waitlists are long, and organs are neither distributed in the order in which recipients signed up, nor by an assessment of the sickest patients' medical needs. Proponents suggest that presumed consent could ease the collective suffering and death of people awaiting organ transplants. Accordingly, presumed consent proponents argue that it maximizes a community good for the benefit of all people, with a relatively small collective burden.<sup>226</sup>

However, presumed or legislative consent policies are too morally problematic to be justified under a social compact theory. Informed consent is the cornerstone of our authorization system, particularly for medical treatment.<sup>227</sup> Morally, it seems more palatable and more ethically prudent to have individuals informed about decisions affecting their lives, particularly their bodies. Of course, part of the justification for informed consent is that the more informed people are, the better decision makers they will become. Well-informed decision makers can

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<sup>223</sup>*Id.* at 1600 (commenting that presumed consent could be viewed as "un-American").

<sup>224</sup>*Id.* See also Dukeminier, *supra* note 164; Pinsley, *supra* note 111 (discussing James Nelson's presumed consent proposal).

<sup>225</sup>Telephone interview with Scott Helm, (Apr. 20, 2000) (providing recent figures for organ waitlists); Telephone interviews with Dr. Ellison, Representative, United Network of Organ Sharing (July, 1999 and Aug., 1999) [hereinafter Ellison Interview].

<sup>226</sup>See Linda Fentiman, *Organ Donations as a National Service: A Proposed Federal Organ Donation Law*, 27 SUFFOLK L. REV. 177 (1997).

<sup>227</sup>Barry D. Kahan, *Organ Donation and Transplantation—A Surgeon's View*, in ORGAN TRANSPLANTATION: MEANINGS AND REALITIES *supra* note 31, at 126, 128-29.

assume greater control and responsibility over their lives, thereby limiting the need for government intervention.

However, legislative consent strips bare informed consent, leaving at best a tacit agreement to be construed as consent.<sup>228</sup> Most importantly, the "people" are left out of legislative consent. An opt-out scheme is not consent, and the true effect of the measure would be to circumvent bona fide consent, thereby sidestepping the involvement of Americans. Moreover, the metaphorical presumption of consent from the legislature cannot override the importance of individual decision-making and autonomy. It seems inappropriate and unsound from a medical perspective that the State could speak about the intimate and personal spheres of death in a collective and distant manner.

Social questions arise when the State is involved in determining how one may use her body.<sup>229</sup> In the context of privacy rights, of course, thoughts on the body and the State's authority to interfere with those rights have far-reaching implications, and, unfortunately, sometimes may be pre-determined by ones gender, sexual orientation, race and socio-economic status. American atrocities in healthcare experimentation illustrate this point. From eugenics and sterilization,<sup>230</sup> to the infamous experiments with destitute black men suffering from syphilis (later known as The Tuskegee Experiments),<sup>231</sup> and raids in the homes of gay men, the American government has played a role in influencing how certain bodies are to be valued, used, and whether some are more expendable or valuable than others.<sup>232</sup> Of course, one could conclude, as many have over the years, that some bodies (e.g.,

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<sup>228</sup>Arguably, one is tacitly agreeing that her body is out of her control if it comes before the coroner for an investigation. This means that presumed consent would be tied to one's behavior or actions. Behaviors such as reckless living or driving might accordingly hasten one's appearance before the coroner. As such, one's behavior predetermines whether or not one will be a donor.

<sup>229</sup>Self-mutilation, suicide and masturbation are three areas where the rules of engagement are not entirely clear.

<sup>230</sup>DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION, AND THE MEANING OF LIBERTY*, 59-76 (1997).

<sup>231</sup>FRED D. GRAY, *THE TUSKEGEE SYPHILIS STUDY: AN INSIDERS ACCOUNT OF THE SHOCKING MEDICAL EXPERIMENT CONDUCTED BY GOVERNMENT DOCTORS AGAINST AFRICAN AMERICAN MEN*, 143 (1998).

<sup>232</sup>Nelson, *supra* note 111.



white ones) are more valuable than others (e.g., those of color),<sup>233</sup> or conversely, that an inalienable right to preserve and protect one's body has been recognized for some more than for others.

Whether scholars or judges will ever agree as to who owns what in the body, it is nevertheless clear from the common law that possession is one of the most fundamental elements indicating property ownership.<sup>234</sup> Perhaps one of the most important questions to be answered is whether or not that ownership or possession can or should be compromised to fulfill a state interest in organ procurement and donation. The *Brotherton* court, closely on point with this question, found that the State's interest was not so substantial as to burden one's property rights in the body. However, in a passionate dissent, Judge Joiner parted ways with the majority, suggesting that much of the common law regarding dead bodies evolved from burial statutes, which were necessarily narrowly tailored to fit such an occasion, and perhaps not intended to address broader issues of property ownership.<sup>235</sup>

Indeed, some courts refuse to address whether a property interest is at stake or not. They focus instead on the value provided to the greater society with what they suggest is limited, if any, abrogation of rights of the deceased or her kin. These courts also seem to insinuate that if a property right was burdened by the State's interest in preserving "the health of the living," such would be properly within the scope of the State's authority, pointing to, perhaps a "social contract"<sup>236</sup> between the State and its citizens.

According to Professor Anita Allen, "social contract theories seek to legitimate civil authority by appealing to notions of rational agreement."<sup>237</sup> Allen states that these theories, referred to in early modern social contractarianism as the "state of nature," are

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<sup>233</sup>See *id.* (noting that "medical research in the nineteenth and even twentieth century reveals, we have been more than willing to subject those who were 'clearly less valuable' to the rigors of research"). See also MILLS, *supra* note 158, at 62 (speaking of blacks as the race most "alienated from their own bodies")

<sup>234</sup>See *Brotherton v. Cleveland*, 923 F.2d 477, 481 (6th Cir. 1991).

<sup>235</sup>*Id.* at 483 (Joiner, J., dissenting) (rejecting the theory of property ownership in dead bodies).

<sup>236</sup>Anita Allen, *Social Contract Theory in American Case Law*, 51 FLA. L. REV. 1, 10 (1999) (noting that "like 'state of nature,' the expression 'social contract' has multiple meanings in the law").

<sup>237</sup>*Id.* at 2.

encompassed by both hypothetical and actual circumstances dealing with politics, law and morality.<sup>238</sup> Allen observes that "[s]ocial contract theories provide that rational individuals will agree by contract, compact, or covenant to give up the condition of unregulated freedom in exchange for the security of a civil society governed by a just, binding rule of law."<sup>239</sup>

Some scholars suggest that social compact theory has been with America since her early days, having what Allen refers to as a special relationship with the United States legal system.<sup>240</sup> This relationship, historians note, influenced the development of the Constitution, the Declaration of Independence, and the Bill of Rights, and they credit it with providing the revolutionary spirit that helped early Americans toil and war for a unified state.<sup>241</sup> Pauline Maier noted that fundamental ideas about public responsibility and duty and political responsibilities in the social compact shaped the American revolutionary movement.<sup>242</sup> This compact had great importance for America's propertied founders, but also those with an "othered" status, as they were perhaps contributors to an agreement that ultimately left them out.<sup>243</sup>

Thus, what this compact means in modern negotiations and relationships may be more difficult to answer.<sup>244</sup> Whether the social compact works for those who have traditionally experienced the American legal, political, and health systems on the margins seems answered by their continued disenfranchisement.<sup>245</sup> Such an inquiry

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<sup>238</sup>*Id.*

<sup>239</sup>*Id.*

<sup>240</sup>*Id.* See also LESSNOFF, *supra* note 220; Will Kymlicka, *supra* note 220; MARION YOUNG, *JUSTICE AND THE POLITICS OF DIFFERENCE* (1990).

<sup>241</sup>Thad W. Tate, *The Social Contract in America, 1774-1787*, 22 WM. & MARY Q. 375 (1965); BERNARD BAILY, *THE IDEOLOGICAL ORIGINS OF THE AMERICAN REVOLUTION* 58-59 (1967); ARTHUR E. SUTHERLAND, *CONSTITUTIONALISM IN AMERICA: ORIGIN AND EVOLUTION OF ITS FUNDAMENTAL IDEAS* (1965).

<sup>242</sup>See PAULINE MAIER, *FROM RESISTANCE TO REVOLUTION* 27 (1972).

<sup>243</sup>According to Professor Allen, America's compact with its citizens spans issues from "sovereignty, slavery, alienage, the negligence rule, criminal incarceration, Congressional nondelegation, land use, the law of finds, public health, self-incrimination, civil forfeiture, debt collection, and the right to privacy." Allen, *supra* note 235 at 6-7 (footnotes omitted).

<sup>244</sup>See MILLS, *supra* note 158, at 62-75 ("arguing that the Racial Contract underwrites the modern social contract and is continually being rewritten.").

<sup>245</sup>DALTON CONLEY, *BEING BLACK, LIVING IN THE RED: RACE, WEALTH, AND SOCIAL POLICY IN AMERICA*, 61-62 (1999) (speaking to blacks continued economic

also points to whether the social compact obligates their involvement. These questions are not only provocative, but aim to point out America's historical inequities as related to certain groups, and ask whether more can be expected from them when they have traditionally received less.<sup>246</sup> Charles Mills, professor of philosophy, argues that the "Racial Contract" undercuts the evolution of the modern version of the contract. The social contract, he argues: "characterized by an antipatriarchalist Enlightenment liberalism, with its proclamations of the equal rights, autonomy, and freedom of all men, thus took place simultaneously with the massacre, expropriation, and subjection to hereditary slavery of men at least apparently human."<sup>247</sup> The contradiction, Mills argues, needs to be reconciled, and it is best conceived or reconciled "through the Racial Contract, which essentially denies their personhood and restricts the terms of the social contract to whites."<sup>248</sup>

Accordingly, the early American social compacts excluded blacks and other nonwhites, frequently finding them outside the American legal, political and social agreement, and therefore not entitled to the privileges and immunities granted whites.<sup>249</sup> According to Francis Jennings, "to invade and dispossess the people of an unoffending civilized country would violate morality and transgress the principles of international law;" however, he reconciled, "savages were exceptional. Being uncivilized by definition, they were outside the sanctions of both morality and law."<sup>250</sup> Whether contemporary policies or the *application* of laws and medical customs perpetuate that philosophy can be examined through case law, policies, and practices.<sup>251</sup> Thus, we

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disenfranchisement).

<sup>246</sup>See MILLS, *supra* note 158, at 64; *Dred Scott v. Sanford, 1856*, in RACE, CLASS, AND GENDER IN THE UNITED STATES 401 (Paula S. Rothenberg, ed., 4th ed. 1998); DAVID E. STANNARD, AMERICAN HOLOCAUST: COLUMBUS AND THE CONQUEST OF THE NEW WORLDS (1992).

<sup>247</sup>MILLS, *supra* note 158, at 63-64.

<sup>248</sup>*Id.* at 64.

<sup>249</sup>See, e.g., C. VANN WOODWARD, THE STRANGE CAREER OF JIM CROW (1955); W.E.B. DU BOIS, BLACK RECONSTRUCTION IN AMERICA (1935).

<sup>250</sup>FRANCIS JENNINGS, THE INVASION OF AMERICA: INDIANS, COLONIALISM, AND THE CANT OF CONQUEST 60 (1975).

<sup>251</sup>See ROBERTS, *supra* note 229; ABRAHAM, *supra* note 2; Noah, *supra* note 37; Randall, *supra* note 38. For a critique of American racial policy or the law in action on education,

must probe beyond the face of the law, to the law as applied or in action.

Presumed consent derives part of its authority from notions of a social contract between the State and its citizens as related to public health.<sup>252</sup> In the past, the State has invoked the social compact to justify its authority in requiring certain obligations of its citizens. Indeed, the State has relied on the social contract to address public health concerns. In *Jacobson v. Massachusetts*,<sup>253</sup> a case involving compulsory vaccinations, the Court referred to the Massachusetts Constitution, arguing that a fundamental principle of the social contract requires that citizens are governed according to a common good, and therefore must sacrifice, comply, and otherwise acquiesce to that "common good."<sup>254</sup>

Judge Joiner's dissent in *Brotherton*, embraces traditional notions associated with social compact theory. Although he refused to acknowledge any property rights in the human body, thereby ignoring America's passion, and indeed her technological prowess with exploring, harvesting and exchanging body parts, his analysis can avoid addressing that issue. He relies on the community good that is performed through the act of organ donation. Throughout his passionate dissent, Judge Joiner reminds us that the State's nonconsensual appropriation of the decedent's eyes would "bring sight and health to the living disabled, and thus to society as a whole."<sup>255</sup> In fact, the community benefit argument may be one of the most salient and compelling arguments articulated by presumed consent supporters, and one of the more difficult to refute. Theoretically, presumed consent saves lives, and Americans have decided that saving lives is a worthy cause for the State. But have Americans chosen to give up informed

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housing, wealth, and employment *see, e.g.*, DERRICK BELL, *FACES AT THE BOTTOM OF THE WELL: THE PERMANENCE OF RACISM* (1992); STEPHEN STEINBERG, *TURNING BLACK: THE RETREAT FROM RACIAL JUSTICE IN AMERICAN THOUGHT AND POLICY* (1995); TOM WICKER, *TRAGIC FAILURE: RACIAL INTEGRATION IN AMERICA* (1996) MELVIN L. OLIVER & THOMAS M. SHAPIRO, *BLACK WEALTH/WHITE WEALTH: A NEW PERSPECTIVE ON RACIAL INEQUALITY*; CONLEY, *supra* note 244.

<sup>252</sup>Fentiman, *supra* note 57, at 1598.

<sup>253</sup>*Jacobson v. Massachusetts*, 197 U.S. 11 (1905).

<sup>254</sup>*Id.* at 27.

<sup>255</sup>*Brotherton v. Cleveland*, 923 F.2d 477, 483 (6th Cir. 1991) (Joiner, J., dissenting).

consent and autonomous decision-making? Arguably they have not, and certainly the response to nonconsensual appropriation of body parts indicates that most Americans are unwilling to compromise on this point.

The arguments supporting presumed consent evoke images of bodies "on loan" to the state, available for whatever uses will best benefit the community.<sup>256</sup> Fentiman talks about presumed consent being a community service, or a duty, like military service.<sup>257</sup> In that context, young men and women surrender their bodies in ready preparedness for combat and possible death for the purpose of preserving the State. However, broad claims of a presumed contract between all citizens and the United States are not only potentially problematic, but they also lack legitimacy.<sup>258</sup>

My purpose in examining the notion of a social contract, which justifies presumed consent, is to illumine what Allen calls the "seductive, malleable fiction" that there exists such a social policy wherein all parties subject to the agreement are treated equitably.<sup>259</sup> America's history with her social contract in many ways mirrors her history with healthcare.<sup>260</sup> In general, women and men of color have been left out.<sup>261</sup> Historically, those who were acknowledged and given

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<sup>256</sup>Fentiman, *supra* note 57, at 1598-1602. Fentiman argues that presumed use of organs would be similar to a national service like that of the military, where individuals serve for the benefit of the "greater community." *Id.* The difference, as the author highlights earlier in this article, is that the flawed allocation system creates a disparity in terms of who in the greater community will be served by such an enormous sacrifice. Accordingly, some argue that a corpse cannot feel the emotional weight of the act, thus perhaps pointing to an inability to be disrespected or betrayed by the act. *Id.* The betrayal could be compared to enlisted soldiers returning from integrated armies to segregated communities.

<sup>257</sup>*Id.*

<sup>258</sup>MILLS, *supra* note 158, at 73.

<sup>259</sup>Allen, *supra* note 235, at 13

<sup>260</sup>See GRAY, *supra* note 230; JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981).

<sup>261</sup>ABRAHAM, *supra* note 2, at 4-5; Denise Grady, *Discrimination Is Painful, It Can Also Be Agonizing*, N.Y. TIMES, Apr. 9, 2000, 4, at 2; Brigid Schulte, *Minorities Face Unequal Health in U.S.: Statistics Show Ethnicities Encounter Higher Illness Rates*, FT. WORTH STAR-TELEGRAM, Aug. 2, 1998, at 1; Editorial, *Institutionalized Racism In Health Care*, THE LANCET, Mar. 6, 1999, No. 9155, Vol. 353, at 765; Ismail Turay, Jr., *Reps Press Minority Health Research*, DAYTON DAILY NEWS Ohio, Feb. 3, 2000, at 3A; Editorial, *Accepted For Too Long The Disparity In Health of White and Black Won't Disappear By Itself*, DES MOINES REGISTER (Iowa), Feb. 25, 2000, at 12.

legitimacy in America's social contract were white, land-owning men.<sup>262</sup> Others hoped to be considered in the contract, and thus bravely shared resources, life, taxes, materials, education, and skills. Some of America's first sons to die in battles for whites to be free were men of color (e.g., fugitive slaves like Crispus Attucks or Native Americans).<sup>263</sup> It is America's history with social contract philosophy and its relation to the legal system that poses potentially problematic results for those who are disenfranchised and marginalized in the organ transplantation and donation systems.

A brief examination of the intersection of law, history, and what Professor Anthony Farley refers to as the colorline, reveals America's disturbing relationship with black Americans.<sup>264</sup> Of course, as slaves, blacks lacked political and legal standing in the United States; they were neither protected by, nor recognized within the context of the law. Moreover, blacks were deprived of social status, and were more often compared with field animals than human beings. Surely part of America's social contract relied on recognition and some form of citizenship which evidently aided in the contract's enforcement. Blacks, even those American-born, were forbidden citizenship, and thus kept out of the benefits of the law.<sup>265</sup> However, this is not to say that blacks were not contributors to America's growth and development; indeed they were, as builders, agriculturists, subjects for scientific

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<sup>262</sup>See MILLS, *supra* note 158.

<sup>263</sup>Mayor Sharon Pratt Kelly, Thurgood Marshall Commemorative Issue: Keynote Address, 35 How. L.J. 61 (1991) (noting that "African Americans, have been in America for four centuries. We have defended America in every war and revolution since Crispus Attucks. We have contributed to her growth, enriched her culture, served her well. It's time for us to claim ownership, to own a piece of the American rock. This is our country and we need to embrace her as such; for we are Americans"); Daniel H. Pollitt, *Reflection on the Bicentennial of The Bill of Rights: The Flag Burning Controversy: A Chronology*, 70 N.C.L. REV. 553 (1992) (commenting on observations that "the first American to fall in the Revolutionary War was Crispus Attucks . . . an African-American who died for freedom a century before our Nation ended slavery"); Constance Baker Motley, *Thurgood Marshall*, 68 N.Y.U. L. REV. 208 (1993) (noting the symbol of heroism and loyalty found in those like Crispus Attucks, commenting that "it was not until Thurgood Marshall's funeral in January 1993 that I came to the full realization that in death he has become an authentic American Hero Crispus Attucks, a Patrick Henry a Thomas Jefferson, a George Washington, an Abraham Lincoln, a Martin Luther King").

<sup>264</sup>See Anthony Paul Farley, *The Black Body as Fetish Object*, 76 ORE. L. REV. 457 (1997).

<sup>265</sup>See RACE, CLASS, AND GENDER IN THE UNITED STATES, *supra* note 245.

experimentation, and educators. They were contributors to a contract that arguably the State breached.

Although America's social contracts are based more on a normative view of law and nature, and not on an actual physical agreement, the terms are basically similar. In the context of, if not an ideal, at least a nearly equitable presumed consent organ-taking and transplantation plan, Americans would collectively suffer a detriment for an equitable community benefit.<sup>266</sup> Thus, all Americans would contribute to a pool for organs, and all Americans would equitably receive from that well.<sup>267</sup> For example, all Americans regardless of race, gender, and socioeconomic distinctions could withdraw from the pool of body parts made available, and progressive efforts would be made to minimize organ rejection, thereby achieving distributive justice. However, an equitable social compact for presumed organ-taking also requires the elimination of social valuing (the process by which some doctors subjectively engage in determining which patients should be referred for organ allocation).<sup>268</sup> After all, economically disenfranchised Americans should not be forced to participate as organ donors and later suffer rejection or indefinite delays as organ recipients.

The social contract sounds ideal; indeed, it gives the impression that all Americans are treated equally and possess the same leverage to bargain for exchanges. However, social contract theory, what Allen refers to as a "metaphor," "can hide what is unpleasant and unwanted, and focus attention on what is pleasant and wanted."<sup>269</sup> In terms of presumed consent, social contract theory can operate to focus on the desired effect of maintaining public health, saving lives, and providing biological materials to aid research. However, hidden behind the social compact, or simply what is not acknowledged, is the racism and social valuing that occurs in the health care industry in general, and

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<sup>266</sup>Fentiman, *supra* note 57, at 1598.

<sup>267</sup>*Id.* But note that Fentiman does not address in any depth how racial disparities would be overcome in her proposal. Neither are the historical racial disparities in healthcare discussed, which seem relevant to a discussion about legislative consent and the presumed donation of organs. One reason for this oversight could be that substantive race discussions in healthcare law, and disparities discussed in the context of civil rights and various other obligations are only recently emerging.

<sup>268</sup>Jefferies, *supra* note 26.

<sup>269</sup>Jefferies, *supra* note 26.

particularly in organ procurement and donation.<sup>270</sup> In this capacity the social compact avoids acknowledging painful racial realities and historical inequities that directly influence why people choose not to voluntarily donate, and why potential recipients of color face innumerable obstacles in the waitlist process.<sup>271</sup> The hidden reality for black Americans is that they are less likely than whites to be selected as organ recipients, are more likely to have longer stays on waitlists, and are more likely to die while waiting on organ lists.<sup>272</sup> In this way, the "coercive dimensions of law" can operate to require certain things from some and not others, all under the misleading heading of community benefit, "consensualism" and "rational self-interest."<sup>273</sup>

Commentators supporting presumed consent policies based on social compact theory must acknowledge that were such a compact to exist, America's present transplantation system reveals a contract worthy of being voided because it lacks accountability and mutual benefit in response to detriment. To explicate, urban, poor Americans are more likely than all other groups to be subjects of presumed consent laws that are attached to autopsy statutes.<sup>274</sup> Mandatory autopsies, as explained earlier, are more likely to occur in connection with certain kinds of deaths that may disproportionately affect economically disenfranchised urban Americans, including deaths by violence, unknown causes, poison, and suicide.<sup>275</sup>

Those more likely to be the subjects of these types of autopsies would be under the control of the coroner or medical examiner who, empowered by statute, is permitted to delegate the removal of the deceased's organs. Other Americans, dying by other means, would not

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<sup>270</sup>*Putting Patients First—Allocation of Transplant Organ: Hearings Before the House Commerce Comm. Subcomm. on Health and The Environment and the Senate Labor and Human Resources Comm. and the Senate Labor and Human Resources Comm.*, 106th Cong., 2nd Sess. (1998) [hereinafter Callender Testimony] (testifying before a Congressional subcommittee about institutionalized racism in healthcare, and particularly in organ allocation).

<sup>271</sup>Gabriella Boston, *Emory Addresses Reluctance of Black Organ Donors*, ATLANTA J. AND CONSTITUTION, May 6, 1999, at 9JA (identifying why blacks are more reluctant to donate, including distrust of the medical community and racism); Roger Campbell, *Too Many Blacks Await Lifesaving Donations*, ESSENCE, Apr. 1999, at 45.

<sup>272</sup>Campbell, *supra* note 270.

<sup>273</sup>Allen, *supra* note 235, at 15.

<sup>274</sup>See, e.g., Frammolino, *Harvest of Corneas*, *supra* note 3.

<sup>275</sup>*Id.*



be subject to present presumed consent statutes, and as such, not obligated to supply organs because their deaths would fall outside of investigative or mandatory autopsy provisions. Therefore, coroners would not have the authority to mutilate their bodies and retrieve organs. Presumed consent policies, in general, are discomfoting because they disregard autonomy, privacy, and a right to choose how one shall have her flesh used in the afterlife.<sup>276</sup> Furthermore, even those highly protected and regarded rights are increasingly threatened and potentially impinged if, as in the case of presumed consent, one belongs to a vulnerable or "othered" community (such as black, latino, homeless, or white poor).<sup>277</sup> Consider how presumed consent worked in Los Angeles only a few years ago: over eighty percent (80%) of the uniformed donors were black and latino, with whites making up only sixteen percent (16%) of the donor pool.<sup>278</sup>

Over the years, the State's involvement with bodies has necessarily influenced how others, namely those in the medical profession, will approach certain bodies.<sup>279</sup> Certainly, when Jefferies points to the amoral consequences of social valuing in organ allocation, he is focusing on practices that directly or indirectly result from a government endorsed system.<sup>280</sup> Jefferies acknowledges that some form of rationing must occur when resources are limited and there is a social necessity to cure and heal. However, he writes, "due to the shortage of organs . . . physicians and other medical personnel make the choice by weighing the patients' social worth."<sup>281</sup> He argues that criteria could include "family-related considerations such as marital status and number of dependents; other criteria are income, educational background, employment record, relationship to authority figures, past

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<sup>276</sup> Jaffe, *supra* note 24, (arguing in general that presumed consent laws impinge on liberty, autonomy, and the right to exclude); Coleman, *supra* note 76, at 19 (commenting that "presumed consent implicates the substantive rights to bodily integrity and to privacy in intimate decisions concerning a person's body")(footnotes omitted); Anderson, *supra* note 65, at 258-63 (arguing that presumed consent supporters ignore the "interests from the donor side of the equation which deserve the most protection").

<sup>277</sup> Frammolino, *Harvest of Corneas*, *supra* note 3.

<sup>278</sup> *Id.*

<sup>279</sup> GRAY, *supra* note 230 (condemning the government-led program which studied the effects of untreated syphilis in black men); JONES, *supra* note 259.

<sup>280</sup> Jefferies, *supra* note 26.

<sup>281</sup> *Id.* at 626.

irresponsible behavior," and intelligence.<sup>282</sup> Unfortunately, Jefferies' enlightening analysis of the inequities found within a "social worth" system end there. Nevertheless, the author does note that "[a] system that decides who lives and dies based on considerations such as income and education is unfortunate and may lead to inequitable results."<sup>283</sup>

Finally, if a social contract in the area of healthcare ever existed between black Americans and the State, and especially with regard to organ transplantation, its compact was breached long ago. Evidence of a social compact in healthcare for black Americans is difficult to muster, and ultimately may be impossible to prove. Although one might suggest that Medicaid and Medicare programs demonstrate a commitment to groups with an "othered" status, especially blacks, such arguments ultimately are weakened by the fact that those government programs limit the types of services one might receive. For example, Medicare covers immune suppressant treatments for only one year after an organ is transplanted.<sup>284</sup> The natural consequences of life without immune suppressant medication could mean rejecting an organ or living in severe discomfort.

Typically, blacks that could benefit from organ transplantation have been kept alive through dialysis, a time consuming and painful process.<sup>285</sup> Thus, for many of America's poorer citizens, organ transplantation was not a possibility, and certainly not one advanced by the State. Donna Shalala's recent campaign to end disparities was hopeful, but results remain to be seen. One could make a very sound argument that a healthcare compact could not exist, and certainly could not be universally applied when Americans lack access to universal healthcare coverage.

Indeed, there are other circumstances of healthcare inequality that challenge the notion of a social compact existing between all Americans and the State. Certainly, America's poor have experienced extreme obstacles to obtaining services ranging from those addressing

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<sup>282</sup>*Id.*

<sup>283</sup>*Id.*

<sup>284</sup>ABRAHAM, *supra* note 2, at 183.

<sup>285</sup>*Id.* Abraham followed Robert Banes through what she refers to as the "transplant game." In this game, black kidney patients are kept alive on dialysis, most hoping for transplants, but some not realizing that they are not on organ transplantation waitlists. *Id.* at 179-97.

mental health needs to prenatal care. Political activists argue that a government reluctant to provide for its poorest and most vulnerable citizens cannot expect the disenfranchised to forego religious practice and sacrifice their bodies, as well as those of their deceased relatives, to satisfy an interest which disproportionately benefits a particularly privileged group.<sup>286</sup>

A social contract, along with any legal transaction, should be granted legitimacy only according to its potential for equitable implementation and results. A compact lacking equitable outcomes for vulnerable populations resembles a coerced confession. In the law, we seek to recognize only those agreements obtained legitimately, outside the reach of duress and coercion. Ultimately, a social compact exists only when a real social relationship exists. In this way, the party subject to the State's compact must be valued, their contributions respected, and their communities honored and afforded the rights and privileges granted through the State's laws and policies.

## PART V. CONCLUSION

Solutions are needed to properly and equitably address America's organ shortage. Those solutions, as Nelson argues, cannot be quick fixes that ignore the historical and contemporary racial dimensions of healthcare. Is it possible to develop solutions for our organ transplantation system without studying and understanding past inequities and injustices? I think not. Our present healthcare system and the relationships between white physicians and black patients are largely informed by inescapable cultural realities. The cultural realities have, in part, helped to shape cultural attitudes and norms with regard to how some bodies are valued and treated. While we would hope that the arms of medicine would operate beyond the reach of race, gender, and socio-economic politics and realities, believing so would be unintelligent, and in light of institutionalized racial oppression, perhaps would be expecting too much.

This history can be overcome by sound reflections on healthcare policies in general, which will ultimately trickle to organ procurement

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<sup>286</sup>See Anderson, *supra* note 65, at 279 n.105 ("voices of concern have already been raised in the African-American community about this problem.").

and allocation. In the meantime, efforts taken by Jim Martin in Kentucky, Kristen McCoy and her staff in Illinois, and transplant procurement officials in Tennessee and Michigan all demonstrate that, with a commitment to education and understanding, more people will donate. In these states they experience an annual surplus of cornea tissue that they are able to release for exportation to states with deficits, the poor, and third world countries.

The central focus of organ procurement strategies should be distributive justice and equity. Those objectives may best be achieved through communication, education, and relationship building. These are not accomplished in a vacuum; rather medical schools must train doctors to be culturally competent so that they can communicate better with patients of color and thus serve their patients more effectively. Also, physicians of color are needed. It is a cultural imperative that the ranks of physicians achieve diversity. Achieving this goal means increasing enrollment and retention of students of color at American medical schools, where numbers of medical doctors of color continue to be exceptionally low.<sup>287</sup>

Building trust in communities of color is crucial. Dr. Clive Callender and other medical scholars have recently expressed such sentiments before Congress and in the national media. More people of color are needed in the discussions about healthcare and the role of law, both as scholars and laypersons receiving services. Accountability from communities of color should not be overlooked (e.g., improving health habits); however, it seems that a moral obligation of fairness and access to healthcare services is owed to communities that have historically experienced racial discrimination in the forms of medical and legal exploitation. Trust must be won. Finally, overcoming racial disparities can be achieved through a more equitable distribution of healthcare services in the physician's office. Patients need information, regular visits with physicians, and better communication about their options.

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<sup>287</sup>Minority populations grew 18.5% between 1975 and 1990, but minority medical school enrollment rose only 7%. Dennis P. Andrulis, The National Public Health and Hospital Institute, *New Dimensions and Directions in Inner-City Health Care*, at <http://www.acponline.org/hpp/pospaper/andrulis.htm>, citing Satcher Rivo, *Improving access to health care through physician workforce reform*, JAMA, 1993 at 270.

