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### THE 2004 ORGAN DONATION RECOVERY AND IMPROVEMENT ACT: HOW CONGRESS MISSED AN OPPORTUNITY TO SAY "YES" TO FINANCIAL INCENTIVES FOR ORGAN DONATION

#### Patrick D. Carlson<sup>\*</sup>

#### INTRODUCTION

In the past twenty years a significant and increasing number of patients have turned to organ transplantation as a means of overcoming life-jeopardizing organ failure.<sup>1</sup> While a sizeable number of individuals receive organ transplants each year,<sup>2</sup> the demand for available organs exceeds the supply, as there are currently over 90,000 individuals on the transplant waiting list.<sup>3</sup> In 2003, the waiting list for cadaveric (deceased) donor transplants increased at more than twice

2. Friedrich Port et al., *Trends and results for Organ Donation and Transplantation in the United States, 2004*, 5 (Part 2) AM. J. TRANSPLANT 843 (2005) ("During 2003, more than 25,000 organs were transplanted in the United States – over 18,000 from deceased donors and almost 7,000 from living donors ... transplants by 2.2% overall ...").

3. United Network for Organ Sharing Online, http://www.unos.org (last visited Jan. 15, 2005).

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<sup>1.</sup> Jennifer L. Hurley, Note, Cashing In on the Transplant List: An Argument Against Offering Valuable Compensation for the Donation of Organs, 4 J. HIGH TECH L. 117 (2004). The increased success and demand for organ transplantation is attributable to the discovery and introduced use of Cyclosporine, an immunosuppressive drug that reduces the incidence of organ rejection. Id. See also S. REP. NO. 98-382, at 13 (1984), as reprinted in 1984 U.S.C.C.A.N. 3975, 3979 ("Associated factors in the growing interest in organ transplantation have been remarkable improvements in morbidity and mortality of patients undergoing organ transplantation, due to improved techniques and the development of immunosuppressive medications which reduce the incidence of rejection of the transplanted organs.").

the rate of the number of transplants.<sup>4</sup> Unfortunately, in the same year, more than 7,000 patients reportedly died while awaiting a transplant.<sup>5</sup>

The organ shortage is costing the lives of patients in need of kidney transplants, because the waiting list for this population is growing at a rate of 3,000-4,000 patients per year.<sup>6</sup> African-Americans disproportionately suffer the effects of the organ shortage as they comprise thirty-six percent of the patients listed in need of a kidney, three times their percentage of the general population.<sup>7</sup>

The success of transplantation in the United States currently depends upon a system of altruistic organ donation from living or cadaveric (deceased) donors.<sup>8</sup> Living donors have been a substantial and steadily increasing source of organs and have exceeded the number of cadaveric donors since 2001.<sup>9</sup> However, the rate of increase in living donors has slowed since 2000.<sup>10</sup> In view of the slowing growth in living organ donation and growing size of the transplant waiting list,

4. Port et al., *supra* note 2 at 843. In 2003, the waiting list increased by 5.1% versus a 1.9% increase in the number of transplants. *Id.* 

6. Gabriel Danovitch et al., Trends and Results for Organ Donation and Transplantation in the United States, 1994-2003, 5 (Part 2) AM. J. TRANSPLANT. 904, 905 (2005).

7. Id. at 905. While the length of time patients wait to receive a kidney has steadily increased for all patients, the increase in time to transplant has been greatest among African Americans who, for those listed in 1999, waited more than twice as long as whites. Id. at 906. This enhanced waiting list burden on African Americans has been due in part to low donation rates among African Americans resulting in antigen mismatching between donors and recipients. Peter Ubel et al., *Pennsylvania's Voluntary Benefits Program: Evaluating an Innovative Proposal for Increasing Organ Donation*, 19(5) HEALTH AFFAIRS 206 (2000). This disparity in time to transplant burdening African Americans may be reduced due to changes in national organ allocation policy de-emphasizing the importance of human leukocyte antigen (HLA) matching. Danovitch et al., *supra* note 6 at 906. However, it is important to note that African Americans who benefit from this policy by receiving mismatched organs previously unavailable may nonetheless experience poorer transplant outcomes as the degree of HLA mismatch has been shown to have some effect on 5-year graft survival outcomes. Id. at 909.

8. Julie T. Sanford & Judith T. Rocchiccioli, Cash for Kidneys: The Use Financial Incentives for Organ Donation, 4(4) POLICY, POLITICS, & NURSING PRACTICE 275, 276 (2003).

9. Francis L. Delmonico et al., Organ Donation and Utilization in the United States, 2004, 5 (Part 2) AM. J. TRANSPLANT. 862, 864 (2005).

10. Id.

<sup>5.</sup> Id.

increasing weight is being placed on cadaveric donors to serve as a substantial source for transplantable organs.

Unfortunately, of the estimated number of individuals eligible to become cadaveric donors each year, in the range of 10,500–13,800, a much smaller number of these individuals actually become donors.<sup>11</sup> Frequently, eligible cadaveric donors fail to become actual donors because family members do not grant consent when approached.<sup>12</sup> For Caucasian families, between 1997-2002, consent for donation was granted only sixty-one percent of the time when requested, and for African-American families, the consent rate was dramatically lower, with consent given only thirty-four percent of the time.<sup>13</sup>

Confronted with this persistent health crisis in organ donation, the 108th Congress responded in 2004 by passing the Organ Donation and Recovery Improvement Act.<sup>14</sup> Congress sought to promote organ donation by enacting measures to enhance public awareness, reimburse costs associated with living-donor organ donation, and improve the organ procurement system.<sup>15</sup> However, Congress failed to adopt provisions that could have opened the door to an innovative alternative to the current singular reliance on altruism: financial incentives for organ donation.

Part I of this Comment will examine the National Organ Transplant Act, the current federal law standing in the way of financial incentives for organ donation by prohibiting the exchange of organs for valuable consideration. Part II will address how Congress missed an opportunity in 2004 to explore financial incentives for organ donation, first, by failing to authorize demonstration projects utilizing financial incentives in cadaveric organ donation, and second, by failing to clearly define the scope of the federal prohibition on the exchange of organs for valuable consideration. Part III will discuss how federal law has inhibited Pennsylvania's effort to respond to the organ shortage by

<sup>11.</sup> Id. at 863, 867 ("The last decade has seen a steady increase in the number of deceased organ donors, from 5099 donors in 1994 to 5985 donors in 2000, and then to 6455 in 2003 . . ."). However, this increase in cadaveric donation has not kept pace with the demand for organs as cadaver organ recovery only increased by fifteen percent from 1992-2002. Robert Arnold et al., *Financial Incentives for Cadaver Organ Donation: An Ethical Reappraisal*, 73(8) TRANSPLANTATION 1361, 1366 (2002).

<sup>12.</sup> Delmonico, *supra* note 9, at 865.

<sup>13.</sup> Id. at 865-66.

<sup>14.</sup> Organ Donation and Recovery Improvement Act, Pub. L. No. 108-216 (2004).

<sup>15.</sup> See id.

increasing cadaveric organ donation through the use of incentives in the form of funeral benefits to donor family members. Finally, Part IV will discuss how the use of funeral benefits is an acceptable companion to altruism, and is workable within the framework of federal law for four reasons. First, it upholds a recognized legal interest family members have in providing a decent burial for their deceased loved ones; second, it serves an important state interest in potentially remedying the serious shortage of organs for transplantation; third, it does not involve a commerce in living-donor organs, contemplated by the drafters of federal law when prohibiting the exchange of organs for valuable consideration; and fourth, it is not exploitative, as it actually serves the interest of minority communities.

#### The National Organ Transplant Act

In 1984, Congress passed the National Organ Transplant Act (NOTA) in response to technological advances in organ transplantation, public appeals by families in need of organ transplants and assistance with associated expenses, and the need to prohibit the burgeoning of a commercial market for organs.<sup>16</sup> With NOTA, Congress first sought to develop a rational, fair, coordinated, and efficient national public/private collaborative organ procurement and transplantation system.<sup>17</sup> Congress then made it "unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration in human transplantation use if the transfer affects interstate commerce."<sup>18</sup> The Congress-imposed penalty for persons who engage in the exchange of human organs for valuable consideration is a \$50,000 maximum fine and/or a maximum five-year imprisonment.19

18. 42 U.S.C. § 274e(a) (2000).

<sup>16.</sup> Lauren R. Siegel, Comment, Re-Engineering the Laws of Organ Transplantation, 49 EMORY L.J. 917, 934 (2000).

<sup>17.</sup> See S. REP. No. 98-382, at 4 (1984). To achieve this objective, Congress created the Organ Procurement and Transplantation Registry, a private nonprofit entity, to maintain a national registry of individuals in need of organs, match and allocate organs based on medical criteria, develop quality standards for organ procurement and transplantation, and assist local organ procurement organizations in equitably distributing and transporting organs to transplant centers nationwide. 42 U.S.C. § 274a-b (2000).

<sup>19.</sup> Id. ("The term 'human organ' means the human . . . kidney, liver, heart, lung, pancreas, bone marrow, cornea, eye, bone, and skin or any subpart thereof and any other human organ . . . specified by the Secretary of Health and Human Services by regulation.").

Under the statute, "valuable consideration" does not include "reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, or lost wages incurred by the donor in connection with the donation of the organ."<sup>20</sup> NOTA was passed with little debate<sup>21</sup> and the Senate Committee on Labor and Human Resources provided only a brief explanation for the prohibition by stating that the "prohibition on the buying and selling of human organs is directed at preventing the for-profit marketing of kidneys and other organs" in the committee's belief that "human body parts should not be viewed as commodities."<sup>22</sup>

The committee distinguished the sale of organs from the sale of blood and blood derivatives, thus the prohibition is not intended to include body products because they "can be replenished" and donation "does not compromise the health of the donor."<sup>23</sup> Ultimately, the committee explained that "the current state of the law was uncertain with regard to the sale of organs," and thus legislation was needed for clarification.<sup>24</sup>

Prior to the enactment of NOTA in 1984, organ donation and transplantation regulation traditionally had been exclusively a matter

- 21. Siegel, supra note 16, at 934.
- 22. S. Rep. No. 98-382, at 4, 16-17 (1984).
- 23. Id. at 16.

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24. Id. at 17.

Id. The Senate Committee on Labor and Human Resources elaborated on 20. this provision recognizing that a person donating a kidney "may sustain expenses from travel, housing, and lost wages, which are not appropriately and fairly reimbursed by voluntary organizations of [sic] federal programs" and thus "it is not the intent of the committee that any such reasonable costs be considered part of valuable consideration." S. REP. NO. 98-382, at 16 (1984). This NOTA exemption for reimbursement for expenses incurred in relation to organ donation and transplantation has prompted Congress and states to introduce or enact legislation aimed at removing the financial dis-incentive of donation through tax relief for donation related expenses. See H.R. 2474, 109th Cong. (2005) (providing that an individual who donates a qualified life-saving organ will be allowed a tax credit in the sum of un-reimbursed costs paid and/or any lost wages in connection with such transplantation); Sean Arthers, Comment, No More Circumventing the Dead: The Least-Cost Model Congress Should Adopt to Address the Abject Failure of Our National Organ Donation Regime, 73 U. CIN. L. REV. 1101, 1102 (2005) ("On January 30, 2004, Wisconsin became the first state in the nation to offer living donors a tax deduction to cover expenses associated with their organ donation.").

of state law.<sup>25</sup> At the time of NOTA's passage, all fifty states and the District of Columbia had adopted, with minor variations, the Uniform Anatomical Gift Act (UAGA), drafted in 1968 by the National Conference of Commissioners on Uniform State Laws to encourage the making of anatomical gifts.<sup>26</sup> The UAGA set out who could make an anatomical gift and how it could be made.<sup>27</sup> However, the Act failed to mention explicitly commerce in organs,<sup>28</sup> thus necessitating Congress' prohibition of selling human organs in NOTA.

The UAGA was amended in 1987 explicitly to outlaw the purchase and sale of organs, reflecting NOTA's prohibition on the sale of organs for valuable consideration.<sup>29</sup> While fewer than half of the states have adopted the amended UAGA with the specific prohibitions on organ sales,<sup>30</sup> in states that have enacted the 1987 version, any currently prohibited financial incentive for organ donation that becomes legal due to a lifting or clarification in NOTA's prohibition may nonetheless remain prohibited by state law.

#### The Organ Donation and Recovery Improvement Act: Congress' Missed Opportunity

In 2004, Congress passed the Organ Donation and Recovery Improvement Act (Organ Donation Act) to respond to the considerable concern over the already large and growing number of

28. Siegel, *supra* note 16, at 933 (noting that "commentators, [nonetheless], interpreted [UAGA] to prohibit the sale of organs").

29. Unif. Anatomical Gift Act § 10 (amended 1987) 8 U.L.A. 62 (2003) ("A person may not knowingly, for valuable consideration, purchase or sell a part for transplantation or therapy, if removal is intended to occur after the death of the decedent.").

30. Siegel, *supra* note 16, at 933. As of 2000, "[o]nly twenty-one states adopted the . . . amended UAGA with the prohibition on organ sales. *See also* Curtis H. Harris & Stephen P. Alcorn, *To Solve a Deadly Shortage: Economic Incentives for Human Organ Donation*, 16 (3) ISSUES L. & MED. 213, 222 (2001).

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<sup>25.</sup> Lloyd R. Cohen, Increasing the Supply of Transplant Organs: The Virtues of a Futures Market, 58 GEO. WASH. L. REV. 1, 8 (1989).

<sup>26.</sup> *Id.* at 6.

<sup>27.</sup> See Unif. Anatomical Gift Act §§ 1-3 (amended 1987), 8A U.L.A. 1–38 (2003) (providing that gifts could be given by any individual of sound mind and eighteen years of age or more and also by relatives in the absence of any objection by the deceased or relatives of greater priority; gifts could made by will, card, or other document).

individuals on the transplant waiting list.<sup>31</sup> In adopting the Organ Donation Act, Congress implemented important measures necessary to improve the current altruism-based organ procurement and transplantation system. However, Congress missed an opportunity to adopt provisions that would have permitted financial incentives that would encourage cadaveric organ donation, a potentially effective policy-alternative response to the organ shortage.

Congress' passage of the Organ Donation Act sought to respond to the growing problem by authorizing the Department of Health and Human Services (HHS) to provide several financial and educational plans. Such plans include funding for public awareness efforts addressing the need for organ donation, awarding grants to organ procurement organizations and hospitals to better coordinate and increase the rate of organ donation, and funding studies to "improve the recovery, preservation, and transportation of organs."<sup>32</sup> The Organ Donation Act also authorized HHS to award grants to states, transplant centers, qualified organ procurement organizations or other public or private entities for providing reimbursement of travel and subsistence expenses incurred by individuals making a living organ donation.<sup>33</sup>

<sup>31.</sup> Organ Donation and Recovery Improvement Act, Pub. L. No. 108-216, 118 Stat. 584 (2004).

See Organ Donation and Recovery Improvement Act at 585-88. 32. Proponents of financial incentives agree that reforms associated with the provisions of this legislation such as "establishing a National Organ Donor Registry, adoption of 'best practices' by Organ Procurement Organizations, raising pay for organ procurement coordinators to reduce their turnover rate, and having organ procurement coordinators in hospitals at all times" are changes "welcome and beneficial, in that they promise to improve the communication of the wishes of the deceased to the family, and to remove from the family the burden of making the difficult decision at that most devastating time, when they have only recently learned that their loved one is brain-dead." Joint Letter to Congress, Home Page of AHCSIOS, The Ad Hoc Committee for Solving the Intractable Organ Shortage, http://www.organgiving.org/proposal.htm (last visited Oct. 3, 2006). [hereinafter Joint Letter to Congress]. Proponents object, however, that such measures only promise to yield more organs from those who have previously volunteered to be donors and likely would not result in an increase in the number of volunteers.

<sup>33.</sup> Organ Donation and Recovery Improvement Act at 584-85. "[Q]ualifying expenses . . . include the expenses of having relatives or other individuals . . . accompany or assist the donating individual."

The provisions Congress adopted in the Act reflect a preference to improve and maintain the solely altruistic scheme of organ donation.<sup>34</sup> While Congress agreed to authorize grants to reimburse living donors for expenses incurred when donating their organs (a form of compensation clearly permissible within the NOTA framework),<sup>35</sup> Congress failed to adopt an earlier Senate version of the Organ Donation Act that would have authorized demonstration projects to determine whether financial incentives would increase cadaveric donation -- projects that would be authorized "notwithstanding" the provisions of NOTA.<sup>36</sup>

Congress also failed to adopt a provision (labeled a "technical amendment concerning organ purchases" in an earlier bill version)<sup>37</sup> that would have amended NOTA's prohibition on organ-for-value exchange by clarifying that valuable consideration excludes "familial, emotional, psychological, or physical benefit to an organ donor, recipient, or any other party to an organ donation event."<sup>38</sup> The

35. S. Rep. No. 98-382, at 4, 16 (1984).

National Kidney Foundation, Organ Donation/Assistance for Living 36. Doctors, http://www.kidney.org/news/newsroom/newsitem.cfm?id=244 (last visited Sept. 11, 2005). The earlier Senate version of the bill, sponsored by Sen. William Frist, authorized the Secretary of Health and Human Services ("HHS") to conduct to three demonstration projects to increase cadaveric donation up "[n]otwithstanding section 301 of the National Organ Transplant Act" ("NOTA"), the provision prohibiting the exchange of organs for valuable consideration, S.573, 108th Cong. §378A (as introduced in Senate, March 6, 2003) (The provisions authorizing limited demonstration projects to increase cadaveric donation were struck from S.573 and not included in the final version passed by the Senate on November 25, 2003). Each project would last no more than three years and would be subject to ongoing ethical review and evaluation by the Secretary of HHS to ensure that the projects would be "administered effectively as possible and in accordance with the stated purpose [to increase cadaveric organ donation within the boundaries of NOTA's prohibition]." Id.

37. S. 573, 108th Cong. § 105 (as introduced in Senate, March 6, 2003)(This provision technically amending NOTA was struck from the S. 573 and not included in the final version passed by the Senate on November 25, 2003).

38. Id.

<sup>34.</sup> The provisions also reflect a continued legislative preference to enact measures that tend to favor living organ donation over cadaveric. See H.R. Res. 2474, 109th Cong. §25(c) (2005) (allowing a tax credit of up to \$5,000 for individuals who donate a qualified life-saving organ and incur unreimbursed costs paid and lost wages in connection with the transplantation); Arthers, *supra* note 20, at 1102 (discussing Wisconsin's action offering living donors a tax deduction to cover expenses associated with their organ donation).

drafters of this provision may have intended to encourage living donation by considering the benefits a living donor would receive after donation, thus ensuring that such benefits are allowed under federal law. However, such clarification of NOTA arguably could attain some legal wiggle room to allow for the implementation of indirect financial incentives in cadaveric organ donation.

Some proponents of financial incentives in cadaveric organ donation have suggested a tightly regulated indirect incentive in the form of a benefit of a set amount that would reward the deceased donor's estate upon the family's decision to "give the gift of life."<sup>39</sup> By providing such an incentive, the decision to donate would arguably yield a "familial benefit" because the remuneration could be used by the family "to help pay for funeral or hospital costs, as a donation to the deceased's favorite charity, or could simply remain with the estate."<sup>40</sup> A family's decision to donate a loved-one's organs would also yield an "emotional" or "psychological" benefit if the funds received were used to memorialize the deceased.<sup>41</sup>

While Congress' decision to preserve the purely altruistic framework of NOTA in the Organ Donation Act is favored by the National Kidney Foundation,<sup>42</sup> other influential groups such as the American

<sup>39.</sup> Joint Letter to Congress, supra note 32 (Proponents have suggested a gift of \$5,000 to the estate of the deceased upon the decision of family members to donate gift to the estate administered by the existing organ procurement organization). Earlier legislation introduced in the 107th Congress by Rep. James Greenwood authorized demonstration projects implementing the use of a financial incentive to encourage cadaveric organ donation in the form of a life insurance policy or annuity payable to a donor's designee upon donation of the deceased's organs, H.R. Res. 5224, 107th Cong. §1 (referred to the Subcommittee on Health, July 29, 2002).

<sup>40.</sup> Joint Letter to Congress, supra note 32.

<sup>41.</sup> See Joint Letter to Congress, supra note 32 (indicating that the gift to the estate of the deceased would be characterized as "society's way of honoring the sacrifice [the family] is being asked to make" and a "token of ... deep and sincere appreciation for [the family's] generosity at [a] most difficult time").

<sup>42.</sup> See National Kidney Foundation, supra note 36. A successful advocacy effort by the National Kidney Foundation ("NKF") resulted in the removal of the provision authorizing demonstration projects exploring the use of financial incentives for cadaveric organ donation. *Id.* Although NKF did not support financial incentives, NKF applauded Congress' steps to assist living donors with financial burdens associated with donation, *id.* Research conducted by NKF's Council of Nephrology Social Workers indicates that 25 percent of potential donors are hesitant to donate due to concerns with the potential financial burden incurred by the living donor. *Id.* The NKF has taken a strong position against

Medical Association,<sup>43</sup> United Network for Organ Sharing (UNOS),<sup>44</sup> American Nephrology Nurses' Association (ANNA),<sup>45</sup> and American Society of Transplant Surgeons (ASTS),<sup>46</sup> have come out in support of

financial incentives as the Board of Directors voted unanimously in 2002 to oppose any policy that would support financial incentives for organ donation. Sanford & Rocchiccioli, *supra* note 8 at 279. According to the NKF chairman, Andrew N. Baur, "[t]here is no way to [provide a financial incentive] and maintain our values as a society . . . [t]he voluntary system we have, free of coercion or commercialization, is the only ethical way medicine can be practiced in the United States." National Kidney Foundation, *supra* note 36. Also taking a strong position, Ellen Gottman-Kulik, chair of NKF's Donor Family Council, commented, "[m]oney is an insult to donor families . . . [a] son or daughter's heart should not be 'worth' \$300 . . . [t]he Gift of Life is a gift and no person's organs should be made into a commodity." *Id* at 1.

43. Bruce Japsen, AMA: Study Paying for Organ Donation, CHICAGO TRIB., June 19, 2002, at Business, 1 (in 2002, the American Medical Association's House of Delegates came out in favor of studies to determine whether money should be used to motivate potential donors and their families). See also Assessing Initiatives to Increase Organ Donations: Hearings Before the Subcommittee on Oversight and Investigations of the H.Comm. on Energy and Commerce, 108th Cong. 108-36 (June 3, 2003) [hereinafter Assessing Initiatives] (statement of Robert M. Sade, M.D., Member of the AMA's Council on Ethical and Judicial Affairs) ("[the AMA has] noted that financial incentives might be an important motivational factor in the context of cadaveric organ donation but that it remains inadequately explored because of federal prohibition."); Sanford & Rocchiccioli, supra note 8, at 279 (although unwilling to endorse financial incentives, the AMA is in favor of studies on incentives that have "clearly measurable outcomes, defined timeframes, use incentives of moderate value, and meet all ethical and scientific design requirements.").

44. Assessing Initiatives, supra note 43 (statement of Robert Metzger, M.D., President-Elect, United Network for Organ Sharing) ("UNOS . . . endorsed the proposal to look at studies and support the study of financial incentives to see if there would be any benefit in the organ donation process with financial incentives.").

45. See Sanford & Rocchiccioli, *supra* note 8, at 279 (taking the position that "research regarding financial incentives for organ donation will give valuable insight into whether these recommendations increase donor supply or deter altruistic donors.").

46. Carey Goldberg, Fiscal Incentive Weighed to boost U.S. Organ Supply, THE BOSTON GLOBE, Oct. 8, 2003, at A1. See also Nicholas D. Kristof, Psst! Sell Your Kidney?, N.Y. TIMES, Nov. 12, 2002, at A27; Assessing Initiatives, supra note 43 (statement of Abraham Shaked, M.D., President of the ASTS) (indicating that the ASTS clearly opposes payment for organs, however, does not oppose efforts to study methods and programs to increase donation rates "that may have a financial component"). Dr. Shaked specifically indicated that ASTS supported the initially pilot programs to explore the use of financial incentives in cadaveric organ donation. The ASTS particularly favors a Pennsylvania initiative to reimburse families for funeral expenses as an incentive for consenting to their loved-one's organ donation.<sup>47</sup> Unfortunately, this initiative has never been implemented due to NOTA's perceived prohibition on financial incentives concerning cadaveric organ donation. This perception remains due to Congress' missed opportunity to clarify NOTA when enacting the Organ Donation Act.

#### Pennsylvania's Innovative but Federally Inhibited Response to the Shortage of Organ Donors

In 1994, the State of Pennsylvania sought to respond to the organshortage by passing legislation creating an Organ Donor Awareness Trust Fund from which family members of deceased donors would be reimbursed for funeral expenses to encourage cadaveric organ donation.<sup>48</sup> However, in 2002, the Pennsylvania Department of Health concluded that the funeral benefit "strayed too close" to violating federal law, specifically NOTA's provision prohibiting offering valuable consideration in exchange for organs.<sup>49</sup> Because of this, the Department scrapped the funeral benefit, and instead, implemented a \$300 stipend per organ donor for food and lodging costs incurred by the donor or the donor's family.<sup>50</sup> Organ procurement organization representatives and the bill's original sponsor disagree with the decision to change the funeral benefit to a food and lodging stipend.

48. 20 PA. CONST. STAT. § 8622 (2001); See also Arnold et al., supra note 11, at 1366 (noting that the fund was subsequently renamed the Robert P. Casey Memorial Fund in honor of the Pennsylvania Governor who was a multiple organ transplant recipient).

49. Sanford & Rocchiccioli, supra note 8, at 278; Christopher Snowbeck, Organ Donor Funeral Aid Scrapped: Health Department Fears Conflict with Federal Law, PITTSBURGH POST-GAZETTE, Feb. 1, 2002, at B1.

50. Snowbeck, supra note 49, at B1.

introduced version of Senator Frist's bill, S. 573, allowing for financial incentive demonstration projects. *Id.* 

<sup>47.</sup> Francis L. Delmonico et al., *Ethical Incentives-Not Payment-For Organ Donation*, 346 (25) NEW ENG. J. MED. 2002, 2004 (2002). The majority of members of an ethics panel for the American Society of Transplant Surgeons support Pennsylvania's proposed program to provide partial reimbursement for funeral expenses. *Id.* ASTS would support a demonstration project that "assessed the effectiveness of providing a modest funeral expense benefit to the donor, not as a payment for a donated organ, but as a token of thanks." *Assessing Initiatives, supra* note 43 (statement of Abraham Shaked, M.D., President, ASTS).

These dissenters contend that this change does little to assist cadaveric donor families.<sup>51</sup> However, Pennsylvania Department of Health officials have defended the decision, explaining that, "covering the costs of food and lodging was not as risky because [NOTA] specifically allows for such reimbursements."<sup>52</sup>

The original Pennsylvania act, adopted in 1994, established a trust fund into which people could contribute when applying for a driver's license or when filing a state income tax return.<sup>53</sup> The act provided that ten percent of the total fund could be expended annually by the Pennsylvania Department of Health for "reasonable hospital and other medical expenses, funeral expenses, and incidental expenses incurred by the donor or by the donor's family in connection with making a vital organ donation."<sup>54</sup> The Pennsylvania Department of Health could spend up to \$3,000 per donor, but payments could only be made directly to the funeral home, hospital, or other service provider related

<sup>51.</sup> Id. While the program may be helpful for living donors, organ recovery experts suggest that the food and lodging benefit will do little to help brain-dead relatives as they usually do not go to restaurants or hotels right after making the decision to donate their loved-one's organs, *id.* See also Ovetta Wiggins, Pa. Organ Donors Get \$300 Boost, PHILA. INQUIRER, May 27, 2002, at A1 (reporting that an organ procurement expert contends that the food and lodging benefit will not achieve what the funeral benefit's advocates wanted to achieve, as the original \$3,000 benefit was substantial and seen as a possible way to increase the number of organs from deceased donors). Rep. Bill Robinson, the sponsor of the original legislation, regards the bill as watered-down and a far cry from what was intended, a benefit that helps families with a major concern after death. Id.

<sup>52.</sup> Snowbeck, *supra* note 49, at B1. As noted earlier, under NOTA, "valuable consideration" does not include "reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, or lost wages incurred by the donor of a human organ in connection with the donation of the organ," 42 U.S.C. § 274e.

<sup>53.</sup> Wiggins, *supra* note 49, at A1. In addition to creating the trust fund, the Pennsylvania act mandated public education programs to increase awareness of the organ shortage, required hospitals to notify organ procurement agencies of every death, and authorized the Governor to create a fifteen-member advisory panel to make recommendations about how the trust fund money should be spent, Sheryl Gay Stolberg, *Pennsylvania Set to Break Taboo on Reward for Organ Donation*, N.Y. TIMES, May 6, 1999, at A1.

<sup>54. 20</sup> PA. CONST. STAT. § 8622 (2001); Margaret M. Byrne & Peter Thompson, *A Positive Analysis of Financial Incentives for Cadaveric Organ Donation*, 20 J. HEALTH ECON. 69, 70 (2001) (as of January 1999, the trust had accumulated \$300,000).

to the donation, ensuring that no part of the fund would ever "be transferred directly to the donor's family, next of kin or estate."<sup>55</sup>

Pennsylvania's proposed funeral benefit trust fund system has received significant support in the organ transplantation community, particularly from the ASTS. The ASTS support is important because it represents a consensus among proponents of altruism<sup>56</sup> and proponents of direct compensation,<sup>57</sup> two camps with compelling yet irreconcilable positions on how to solve the organ shortage problem. The ASTS chose to support a funeral benefit system after assembling a panel of ethicists, organ procurement organization executives, physicians, and

56. Proponents of altruism believe that organs should be given and not paid for in the belief that payment degrades fundamental values of life and liberty and fosters class distinctions and exploitation. Delmonico et al., *supra* note 45, at 2004 ("These values are degraded when a poor person feels compelled to risk death for the sole purpose of obtaining monetary payment for a body part."). Payment for organs is also objected to on religious grounds as a violation of the dignity of the human person, captured in the following statement by Pope John Paul II:

[Donating an organ] is not just a matter of giving away something that belongs to us but of giving something of ourselves, for by virtue of its substantial union with a spiritual soul, the human body cannot be considered as a mere complex of tissues, organs and functions ... rather it is a constitutive part of the person who manifests and expresses himself through it. Accordingly, any procedure which tends to commercialize human organs or to consider them as items of exchange or trade must be considered morally unacceptable, because to use the body as an 'object' is to violate the dignity of the human person.

Arnold et al., *supra* note 11, at 1362-63. Proponents of altruism also fear undesirable consequences from organ sales such as donors withholding medical information that results in the transmission of disease and families induced to prematurely withdraw care of loved-ones if death is linked to the sale of organs, *id.* at 1362.

57. Proponents of compensation take the ethical position that the objective of saving patients' lives should trump the natural desire to impose personal moral or philosophical attitudes on others, Andrew H. Barnett et al., *Improving Organ Donation: Compensation Versus Markets*, 29 INQUIRY 372, 372 (1992). Thus, if compensation will better achieve the objective of saving lives, it should be permitted, *id.* at 373. Libertarian proponents of payment hold that "autonomy rights of individuals are paramount, and that those rights encompass the ability to sell one's body or organs," Arnold et al., *supra* note 11 at 1363.

<sup>55. 20</sup> PA. CONST. STAT. § 8622 (2001). The Pennsylvania plan was intended to be "a voluntary death benefit for a family who gave a gift" and not the buying and selling of organs, according to Howard Nathan, a member of the advisory committee recommending the plan, Donald Joralemon, *Shifting Ethics: Debating the Incentive Question in Organ Transplantation*, 27 J. MED. ETHICS 30, 31 (2001).

surgeons, considering forms of financial incentives.<sup>58</sup> Panel members found funeral benefits to be the best mechanism for increasing the supply of organs while maintaining the ethical preference for preserving the gift concept in organ donation.<sup>59</sup> A funeral benefit was viewed as a suitable alternative within the current altruistic structure of donation because it preserved an essential ethical perception of gratitude in organ exchange.<sup>60</sup> Panel members preferred a funeral benefit over other financial incentive forms, such as direct payment or an income tax credit, because such forms were more likely to be perceived as a "purchase of a commodity," rather than as a "thank you" on behalf of society.<sup>61</sup>

58. Arnold et al., *supra* note 11, at 1361; *Assessing Initiatives, supra* note 43 (statement of Abraham Shaked, M.D., President of the ASTS) ("ASTS would support a demonstration project that assessed the effectiveness of providing a modest funeral expense benefit to the family of a decedent donor, not as a payment for a donated organ, but as a token of thanks.").

Arnold et al., supra note 11 at 1365. The panel members supported the 59. ethical propriety of a funeral benefit as it best balances the two goals of holding to a purely altruistic system in a capitalistic system and the potential for a more effective method of procuring organs. Id. Panel members believed that a benefit in the range of \$600 - 3,500 would be an acceptable "limited" reimbursement amount given that the cost of a funeral in this country is likely to be at least several The group also approved of the use of a thousand dollars. Id. at 1366. contribution to a charitable organization at the direction of the family as ethically acceptable as long as the amount was not large as to become an excessive The panel members decided that a charitable inducement. Id. at 1364. contribution in the range of \$500 - 1500 would an acceptable amount. Id. at 1366.

60. Id. at 1364, 1367. Direct payment and an income tax credit were disfavored as they would not fulfill the ethical principles of "preserv[ing] the concept of a gift, convey[ing] gratitude for the gift, avoid[ing] commodifying organs, honor[ing] the deceased, not alter[ing] the care of the donor, or maintain[ing] the public trust in the integrity of the organ supply," id. at 1364. The panel acknowledged, however, that its advocacy for a funeral benefit may be perceived as a "laundered form of compensation [or] [a]t best, it could appear to be inconsistent," given its unanimous support for the concept of altruism and its opposition to a direct payment. Id. at 1365. See also Edward W. Nelson et al., Financial Incentives for Organ Donation: A Report of the Payment Subcommittee, United Network for Organ Sharing Ethics Committee (June 30, 1993), http://www. unos.org/Resources/bioethics.asp?index=3 [hereinafter UNOS Report] (noting that proponents of financial incentives have characterized the concept as "rewarded gifting," but opponents criticize this term as an oxymoron and a "despicable euphemism").

61. Arnold et al., *supra* note 11, at 1364 (Figure 1).

Pennsylvania's legislative initiative and the ASTS panel's support for a funeral benefit incentive system should be a signal to national policy makers that there is considerable support in the organ transplantation community and among the public for exploring alternatives to the current solely altruistic approach to organ donation. The funeral benefit incentive is the result of a successful public deliberation where proponents of opposite positions<sup>62</sup> have come to an agreement on ways to address the organ shortage.<sup>63</sup> It is essential that Congress seize the moment by funding demonstration projects to test the use of funeral benefits and act to clearly define NOTA's prohibition on exchanging organs for valuable consideration, so that states, like Pennsylvania, can respond to the needs of those waiting for a life-saving organ.

#### A Funeral Benefit to Donor Families is a Workable Compliment to Pure Altruism as it Serves Important Interests Within the Framework of NOTA

An incentive in the form of funeral benefits to deceased donor family members is a reasonable policy innovation within the framework of NOTA that augments pure altruism and addresses the shortage of cadaveric organs. A funeral benefit serves important interests within the framework of NOTA: first, it serves the family's interest in possessing and controlling the body for final disposition; second, it serves the state's interest in having an effective life-saving

<sup>62.</sup> For a statement of support by an altruism proponent, see Delmonico et al., supra note 47, at 2003 ("Reimbursement for funeral expenses [is different than a tax credit because it] is intended as an expression of society's appreciation for the donation, and it is consistent with the provision for reimbursement of the expenses of donation after the declaration of death."); For a statement of support by proponents of compensation, see Joint Letter to Congress, supra note 32 ("We believe we have a compromise plan that both comports with human dignity and constitutes the tiniest imaginable step toward utilizing the power of financial incentives to bring the supply of cadaveric organs up to meet the demand.").

<sup>63.</sup> Ethicists and philosophers, such as John Rawls, could reasonably recognize the consensus on the funeral benefit as an excellent example of "public reason," in which citizens of a "well-ordered society" with different (and ultimately irreconcilable) philosophical views and moral and religious beliefs find a set of values and principles that each can publicly endorse. Cynthia B. Cohen, *Promises* and Perils of Public Deliberation: Contrasting Two National Bioethics Commissions on Embryonic Stem Cell Research, 15(3) KENNEDY INST. ETHICS J. 269, 274-75 (2005). Proponents of altruism and compensation came together to fashion a policy of shared values by preserving the concept of gift while endorsing the use of a financial incentive that will effectively increase organ supply, saving lives. Id.

organ allocation system; third, it does not involve a commerce in living donor organs; and fourth, it is not exploitative and serves the interests of minority communities.

#### The Family's Interest in the Body

A funeral benefit incentive is an excellent policy alternative since it serves an overlooked interest: family members' common law-recognized control over the body of their deceased.<sup>64</sup> Although courts have differed somewhat in how they characterize this interest, with some regarding it as a "property" right, and others regarding it as a "quasi-property" right,<sup>65</sup> the essence of the interest is the same under both views: a limited interest to possess and control the body in order to fulfill the duty of decent disposition.

Courts have defined the boundaries of the family's interest in the body of their deceased in a series of cases involving a coroner's removal of body parts without consent of family members.<sup>66</sup> In *Brotherton v. Cleveland*,<sup>67</sup> the court held that a wife had a recognized property interest in her deceased husband's corneas that rose to the level of a "legitimate claim of entitlement," protected by the due process clause of the Fourteenth Amendment.<sup>68</sup> The court recognized

65. Samantha A. Wilcox, Comment, Presumed Consent Organ Donation in Pennsylvania: One Small Step for Pennsylvania, One Giant Leap for Organ Donation, 107 DICK. L. REV. 935, 947.

66. Cases have frequently involved the removal of corneal tissue by coroners or medical examiners pursuant to state statutes authorizing removal for transplantation.

67. Brotherton v. Cleveland, 923 F.2d 477 (6th Cir. 1991).

68. Id. at 480 (quoting Memphis Light, Gas & Water Div. v. Craft, 436 U.S. 1, 9, (1978)). See Melissa A.W. Stickney, Property Interests in Cadaverous Organs: Changes to Ohio Anatomical Gift Law and the Erosion of Family Rights, 17 J. L. & HEALTH 37, 56 (2004) (providing and in-depth analysis of Brotherton). Because the plaintiff's interest rose to the level of a legitimate claim of entitlement and the removal of the deceased's corneas was under the authority of established state procedures, the wife was entitled to a necessary deprivation process. Brotherton, 923 F.2d at 482. See also Whaley v. County of Tuscola, 58 F.3d 1111, 1116 (6th Cir. 1995) (following Brotherton in the view that the next of kin have a constitutionally

<sup>64.</sup> Eric S. Jaffe, "She's Got Bette Davis[s'] Eyes": Assessing the Nonconsensual Removal of Cadaver Organs Under the Takings and Due Process Clauses, 90 COLUM. L. REV. 528, 543 (1990) ("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."); Siegel, supra note 16, at 927-28 ("Courts generally recognize a quasi-property right in the relatives of the decedent.").

this interest in the body as "substantial," even though extremely regulated.  $^{69}$ 

This property interest in the body of the deceased was further explained in a factually similar 2002 federal opinion, Newman v. Sathyavasglswaran.<sup>70</sup> In Newman, the court held that parents had "exclusive and legitimate claims of entitlement to possess, control, dispose and prevent the violation . . . of the bodies of their deceased children."<sup>71</sup> The court explained that this right of the family over the deceased's body is "deeply rooted in our legal history and social traditions," and serves a "duty to protect the dignity of the human body in its final disposition."<sup>72</sup>

Other courts have viewed the interest as less substantial, characterizing it as a "quasi-property" right rather than a property right. In *Georgia Lions Eye Bank v. Lavant*,<sup>73</sup> the court finds a more limited view than the common law concept of "quasi property in recognition of the interests of surviving relatives in the possession and control of decedents' bodies" is not of constitutional dimension.<sup>74</sup>

69. *Brotherton*, 923 F.2d at 482. The court noted that "[t]he prevailing view of both English and American courts eventually became that next of kin have a 'quasi-property' right in decedent's body for purposes of burial or other lawful disposition" (citing Spiegel v. Evergreen Cemetery Co., 186 A. 585, 586 (1936)).

70. Newman v. Sathyavaglswarn, 287 F.3d 786 (9th Cir. 2002) (parents whose deceased children's corneas were removed by a county coroner's office without notice or consent were permitted to bring a 42 U.S.C. § 1983 action as the county's deprivation of the corneas constituted a deprivation of due process under the Fourteenth Amendment).

71. Id. at 796.

72. Id.

73. Georgia Lions Eye Bank v. Lavant, 335 S.E.2d 127, 128 (Ga. 1985) (the mother of a deceased infant brought suit claiming wrongful removal of corneal tissue following death pursuant to statute).

74. *Id.* at 128-129 (holding that there was no violation of due process as the state's General Assembly had "within its power, in the interest of public welfare, to authorize this procedure, which yearly benefits hundreds of Georgians."). *See also* Bauer v. N. Fulton Med. Ctr., Inc., 527 S.E.2d 240, 244 (Ga. Ct. App. 1999) ("The quasi-property right in a corpse is not pecuniary in nature, nor should it be. The right encompasses only the power to ensure that the corpse is orderly handled and laid to rest, nothing more."); Colavito v. New York Organ Donor Network, Inc., 356 F.Supp.2d 237, 246 (E.D.N.Y. 2005) ("the narrow rights in a deceased's body are reserved exclusively for the next of kin and only for purposes of ensuring

protected property interest in the dead body of a relative); Mansaw v. Midwest Organ Bank and Truman Med. Ctr. W., No. 97-0271-CV-W-6, 1998 WL 386327, at 8 (W.D.Mo. July 8, 1998).

Although *Lavant* held a more limited view of this right than did *Brotherton* and *Newman*, the *Lavant* court, nonetheless, acknowledged that a common law interest existed in the next of kin over the body of the deceased.<sup>75</sup>

This "quasi-property" limited view of the rights of family members over the body of the deceased was also found in *State v. Powell*,<sup>76</sup> where the court held that no constitutional due process violation occurred when a medical examiner removed corneas without parental authorization, as permitted by statute.<sup>77</sup> However, what is significant is that the court in a later decision rejected *Powell's* broad language recognizing no constitutionally protected property interest, and instead, embraced *Brotherton's* view that next of kin have a "legitimate claim of entitlement... to possession of the remains of a decedent for burial or other lawful disposition" and that this interest is entitled to constitutional protection.<sup>78</sup> The *Crocker* court also suggested that the right of next of kin to possess the decedent's remains for disposition is

proper disposition of the deceased's body. Courts have consistently stated that it is against public policy to recognize broad property rights in the body of a deceased."); Perry v. Saint Francis Hosp. and Med. Ctr., Inc., 886 F.Supp. 1551, 1563 (D. Kan. 1995) ("Kansas common law on this matter is no different from the position universally held by other states which recognizes no property right, commercial or material, in the corpse itself but only a right of possession in order to dispose of the corpse appropriately.").

75. Georgia Lions Eye Bank, 335 S.E.2d at 128. In considering the nature of the family's right to the body, the court referenced a rather skeptical view on the "quasi-property right" by W.L. Prosser, "It seems reasonably obvious that such 'property' is 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 to deceive no one but a lawyer." *Id.* However, the court then noted that while there is no recognized property right in a dead body at common law, the courts of "civilized and Christian countries regard respect for the dead as not only a virtue but a duty, and hold that ... a quasi property right belongs to the husband or wife, and, if neither, to the next of kin." *Id.* 

76. State v. Powell, 497 So. 2d 1188 (Fla. 1986).

77. *Id.* at 1191 (commenting that "[a]ll authorities generally agree that the next of kin have no property right in the remains of a decedent.").

78. Crocker v. Pleasant, 778 So. 2d 978, 988 (Fla. 2001). The court in *Crocker* explained that *Powell* merely held that a Florida statute pertaining to corneal tissue removal was constitutional after finding that the state's interest in obtaining suitable corneal tissue far outweighed the "infinitesimally small intrusion" incident to corneal removal. *Id.* at 985. The state's intrusion in *Crocker* was significantly greater as a city and county buried the twenty-three year old son of the plaintiffs after making virtually no effort to notify them of his death. *Id.* at 980. The parents only came to know of their son's burial after filing a missing person's report. *Id.* 

based on a need to "celebrate the life of the deceased 'through appropriate commemoration."<sup>79</sup>

Brotherton, Newman, and Crocker reveal that courts have been inclined to view family members' interests in the bodies of their deceased as substantial and of constitutional dimension. Even courts that recognize this interest as one of "quasi property," and thus not rising to the level of constitutional protection, nonetheless recognize that interests to possess and control remains exist under the common law. As Newman and Crocker suggest, the purpose of this interest is to enable family members to fulfill their societal duties to protect the body's dignity in its final disposition and to celebrate the life of the deceased through appropriate commemoration.<sup>80</sup>

A financial incentive in the form of a funeral benefit serves the important court-recognized societal interest family members have over their deceased's bodies. By allowing family members to voluntarily accept assistance with funeral expenses, next-of-kin are enabled to exercise their rights and fulfill their duties to memorialize and provide a decent disposition of their deceased. Conversely, the federal law, by prohibiting family members from receiving assistance for funeral expenses, next-of-kin are hindered in exercising and performing legally protected rights and duties.

# The State Interest of Major Significance: An Increase in Organ Donation

In addition to serving family members' interests in their deceased's bodies, a funeral benefit incentive serves an important state interest in supporting an effective and life-saving organ procurement and transplantation process.<sup>81</sup> When NOTA was enacted in 1984, Congress

<sup>79.</sup> Id. at 985.

<sup>80.</sup> Newman v. Sathyavaglswarn, 287 F.3d 786, 796 (9th Cir. 2002); Crocker, 778 So. 2d at 985.

<sup>81.</sup> In addition to saving lives due to increased donation, proponents of financial incentives for organ donation point out that paying for organs would be cost-effective. UNOS Report, supra note 60 ("[1]f 500 additional donors and therefore 1,000 additional cadaveric kidneys were gained [from the use of a financial incentive scheme], the potential savings to the medical care system would be over \$30 million, many times the initial incentive outlay."); Kristoff, supra note 46, at A27 (noting that "paying for organs would be cost-effective, because dialysis costs much more than a transplant operation itself"). According to scholars who have researched the cost of dialysis in comparison to transplantation, a successful kidney transplantation saves as much as \$60,000 per end-stage renal disease patient over a five-year period. DAVID L. KASERMAN & A. H. BARNETT, THE U.S.

believed it necessary for the federal government to act to "encourage organ donation and improve procedures for efficient organ procurement leading to successful transplantation."<sup>82</sup> A funeral benefit incentive furthers this important state interest by encouraging organ donation from individuals who are not inclined to donate within the current framework of pure altruism.<sup>83</sup> Since NOTA's enactment, the insistence on pure altruism as the exclusive means through which organs can be procured has been insufficient in meeting the need for organ donors.<sup>84</sup>

Courts have recognized the states' interests in implementing policy that encourages organ donation. In *Mansaw v. Midwest Organ Bank*,<sup>85</sup> the court rejected a challenge to a pro-organ transplant statute as the state had a "legitimate and compelling interest in providing for and

ORGAN PROCUREMENT SYSTEM 34-35 (Marvin H. Kosters, ed., The AEI Press 2002). The Health Care Financing Administration, the federal underwriter for dialysis under Medicare, could gain substantial savings if all suitable renal patients on the waitlist received transplants. *Id.* 

82. S. Rep. No. 98-382, at 4 (1984).

See Thomas G. Peters, Life or Death: The Issue of Payment in Cadaveric 83. Organ Donation, 265 (10) J. AM. MED. ASS'N. 1302, 1302-3 (1991). Altruism as the sole reason for cadavaric organ recovery is a belief that persists in the medical community possibly based on "the incorrect assumption that altruism emerges with counseling and education, that altruistic behavior should prevail in this matter, and that persons unwilling to exhibit altruistic behavior should not be coerced into any other behavior as this coercion would impinge on free personal decision making." Id at 1301. Peters suggests, instead, that some population groups harbor different thoughts and feelings about organ donation and do not operate under the same established social mores as the medical community does, which hold altruism as the only motivation for organ donation. Id. But see Amitai Etzioni, Organ Donation, A Communitarian Approach, 13(1) KENNEDY INST. OF ETHICS J. 1, 6 (2003) (conceding that altruism is often an insufficient motive for action, but instead, arguing that moral persuasion is a better way to encourage organ donation than monetary incentives). Under Etzioni's view, it is better to make organ donation "a part of one's sense of moral obligation, something one cannot look in the mirror or face friends without having lived up to." Id.

84. Steve P. Calandrillo, Cash for Kidneys? Utilizing Incentives to End America's Organ Shortage, 13 GEO. MASON L. REV. 69, 83 (2004). While a study has shown that "81% of Americans support the concept of voluntary organ donation . . . only about one-quarter have actually signed up as registered donors" and many families refuse to give consent to organ donation. Id.

85. Mansaw v. Midwest Organ Bank & Truman Medical Center West, No. 97-0271-CV-W-6, 1998 WL 386327, at \*7 (W.D.Mo. July 8, 1998) (upholding a Missouri statute that required the consent of only one parent to donate a deceased child's organs). securing a future for the living.<sup>86</sup> The court noted that the state's purpose in addressing the organ shortage "is of major significance not only to those currently on waiting lists, but to all persons who may at any time find themselves or a close family member in desperate need of an organ.<sup>87</sup>

In upholding the pro-organ donation statute in *Mansaw*, the court justified limiting the rights of a parent over the body of a deceased child, because the statute expressed a societal belief that "all that can be done should be done to help the living."<sup>88</sup> The court was in the position of having to weigh the conflicting interest of family members in the body of their deceased with the state's significant interest in increasing the supply of transplantable organs. In contrast, a funeral benefit incentive furthers the significant state interest of encouraging organ donation and simultaneously allows family members to exercise their rights and societal responsibility to possess and control the body for commemoration and decent disposition. Thus, a funeral benefit incentive achieves the goals of securing a future for the living while honoring the life of the deceased.

#### A Funeral Benefit does not Involve a Commerce in Living Donor Organs Congress Sought to Prevent

When Congress enacted NOTA, making it "unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation,"<sup>89</sup> Congress sought to prohibit a commerce in living donor organs that differs significantly from an indirect incentive like funeral benefits that

<sup>86.</sup> Id. at 8 (holding that a parent's property interest in his son's body "may reasonably be disregarded, at least when the other joint property owner has consented and Plaintiff's interest must yield to the greater rights of the State—and our society—in carrying out its public policy.").

<sup>87.</sup> Id. at 7. See also State v. Powell, 497 So. 2d 1188 (Fla. 1986) (holding that the societal needs for corneal tissue outweigh individual concerns in view of a proorgan donation statute that has undisputedly increased the supply and quality of tissue available for transplantation); Georgia Lions Eye Bank v. Lavant, 335 S.E.2d 127, 129 (Ga. 1985) (concluding that the Georgia General Assembly certainly has within its power, in the interest of the public welfare, to authorize the removal of corneas without consent under certain conditions as the procedure yearly benefits hundreds of Georgians).

<sup>88.</sup> Mansaw, 1998 WL 386327, at \*7.

<sup>89. 42</sup> U.S.C. § 274(e) (2000).

encourage cadaveric organ donation.<sup>90</sup> Congress intended to prevent the development of a market in living donor organs where organs would be treated as commodities and articles for trade. Congress believed it undesirable to permit the buying and selling of organs in which brokers, procuring and allocating organs through an auction, could profit from the exchange.<sup>91</sup> The NOTA drafters were essentially advocating that it is unethical to treat living donor organs as a fungible good,<sup>92</sup> inequitable to distribute organs based on ability to pay,<sup>93</sup> and

90. John A. Sten, Comment, *Rethinking the National Organ Transplant Program: When Push Comes to Shove*, 11 J. CONTEMP. HEALTH L. & POL'Y 197, 216 (1994) ("[I]t is indisputable that Congress intended to prevent the commercialization of the human body. But there is no evidence that Congress meant to prohibit all organ procurement procedures that employ financial incentives yet operate in a non-market environment.").

91. The concerns about organ commerce are reflected in the Senate report accompanying NOTA, stating that "the prohibition on the buying and selling of human organs is directed at preventing the for-profit marketing of kidneys and other organs." S. REP. NO. 98-382, at 4 (1984). The report later adds, "[i]t is the sense of the committee that individuals or organizations should not profit by the sale of human organs for transplantation." *Id.* at 16.

92. See infra note 97 and accompanying text. In treating living donor organs as a fungible good, ethicists argue that the dignity of human beings is not respected because donors are reduced to parts and assigned a price, inappropriately equating parts of living persons with other non-human goods. STEPHEN WILKINSON, BODIES FOR SALE: ETHICS AND EXPLOITATION IN THE HUMAN BODY TRADE 45 (2003). Ethicists ascribing to this view see no difference between treating parts of the body as objects of commerce and treating human beings as such because "personal identities are intimately and inextricably connected to our bodies." Carson Holloway, Monetary Incentives for Organ Donation: Practical and Ethical Concerns, in ORGAN AND TISSUE DONATION: ETHICAL, LEGAL, AND POLICY ISSUES 143, 152 (Bethany Spielman ed., 1996). But see infra note 100 (discussing scholars who challenge this position).

93. See infra note 99 and accompanying text; Shelby E. Robinson, Comment, Organs for Sale? An Analysis of Proposed Systems for Compensating Organ Providers, 70 U. COLO. L. REV 1019, 1046 (1999) (contending that "many people could easily be priced out of obtaining a life-saving kidney" under a market-driven arrangement in live organs); Calandrillo, *supra* note 84, at 93 ("[B]anning human organ sales could be justified on distributive justice grounds: the law would prevent poor people from becoming the only 'sellers,' and it would provide both poor and wealthy individuals equal access to those organs being supplied – regardless of their ability to pay.").

risky to permit organ brokerage because it could compromise the health of donors and recipients.<sup>94</sup>

Congress was primarily acting in reaction to an idea of a Virginia physician, Dr. Barry Jacobs, who planned to form the International Kidney Exchange Ltd., where kidneys would be procured from indigent third-world residents, organ providers would set a price for their kidneys, and Jacobs would collect \$2,000 to \$5,000 from the buyer for the brokerage services.<sup>95</sup> In response to Jacob's plan and a similar effort by another company in New England, then-Rep. Albert Gore, Jr. sponsored NOTA's prohibition on the exchange of organs for valuable consideration.<sup>96</sup> Legislative history suggests that Gore's primary concerns behind NOTA's prohibition were that a market for human organs would result in an unethical commodification of the

95. Robinson, *supra* note 93, at 1036. Jacobs sent letters to 7,500 hospitals about his plan and received responses from several indicating an interest in removing kidneys from healthy donors Jacobs planned to solicit. Margaret Engel, *Va. Doctor Plans Company to Arrange Sale of Human Kidneys*, WASH. POST, Sept. 19, 1983, at A9. According to Jacobs, "preliminary research showed that potential donors set a price of up to \$10,000 for one of their kidneys." *Id.* Jacobs planned to overcome the illiteracy of potential donors by obtaining informed consent via videotape, Harris & Alcorn, *supra* note 30, at 231. *See also* Walter Sullivan, *Buying of Kidneys of Poor Attacked*, N.Y. TIMES, Sept. 24, 1983, at A19.

96. Sullivan, supra note 95, at A19. See also Joralemon, supra note 55, at 30.

See infra note 98 and accompanying text. It is argued that a market for 94. human organs from living donors presents the risk that sellers pressured by poverty will underestimate the risks involved in organ sales. Calandrillo, supra note 84, at 95. Once a sale occurs, the donor incurs irreversible risk that his remaining kidney could fail. Id. at 96. A donor may also experience a deterioration in health following an organ donation. Id. at 95. Because of this concern, the state has an interest in protecting the mental and physical health of potential sellers against risks unappreciated by donors. Id. Research on the kidney trade in India confirms some of these fears. In a survey of 305 Indians who sold a kidney, nearly all sold to pay debts. Madhav Goyal et al., Economic and Health Consequences of Selling a Kidney in India, 288 J. AM. MED. ASS'N 1589, 1590 (2002). In addition, the study revealed that nephrectomy was associated with a decline in health status and half of individuals surveyed complained of persistent pain at the nephrectomy site. Id. at 1591-92. When asked what advice they would give to individuals with the same reasons they had for selling, seventy-nine percent of the respondents indicated that they would not recommend selling a kidney. Id. However, one should note that the concerns pertaining to a market for living donor organs do not apply when considering a financial incentive for cadaveric organ donation, as the individual does not become eligible for donation until death has occurred, see infra note 106 and accompanying text.

human body,<sup>97</sup> would compromise the health of the donor,<sup>98</sup> and exploit the poor.<sup>99</sup>

The comments in the report accompanying NOTA, as well as the context in which it was passed, and the views of its chief sponsor all suggest that Congress was seeking to prohibit a profit-motivated commerce in living donor organs, where a brokered organ sale could compromise the health of the donor.<sup>100</sup> However, a funeral benefit

97. National Organ Transplant Act: Hearing on H.R. 4080 Before the Subcomm. on Health and the Environment of the H. Comm. on Energy and Commerce, 98th Cong. 128 (1983) [hereinafter NOTA Hearings] ("It is against our system of values to buy and sell parts of human beings. It is against our system of values to auction off life to the highest bidder.").

98. *Id.* at 129. In distinguishing the buying and selling of organs from the buying and selling of blood, Gore commented,

Blood is unusual, and once given, it is still retained. The individual who donates blood suffers no harm. A doctor who takes blood from someone isn't violating the Hippocratic oath by doing harm. The Hippocratic oath says, first, do no harm. A doctor who carves into a healthy person to take a kidney simply for money is violating the Hippocratic oath.

Id. This concern over the health of the donor is also reflected in language of the Senate report accompanying NOTA, the prohibition on profiting off of organ donation "is not meant to include blood and blood derivatives, which can be replenished and whose donation does not compromise the health of the donor." S. Rep. No. 98-382, at 16-17 (1984).

99. NOTA Hearings, supra note 97, at 126. Gore explained:

There is no need to risk the problems a for-profit organ procurement system conjures up . . . [t]hese proposals have only served to exploit the desperation of Americans who are pressed by the serious economic troubles our nation is experiencing. Selling a part of their body is not the answer to their problems and it is not the answer for those awaiting transplants.

Id.

100. It is important to note that scholars question the assumption that it is unethical to address the shortage of available organs for transplantation through an organ market. Lloyd Cohen challenges the assumption that a market in human organs is offensive to human dignity with the following question, "Which is more offensive to human dignity: the use of market forces to increase the supply of life-extending vital organs or criminally punishing the use of the market to harness self-interest in the cause of saving the lives of thousands of people who are dying for want of organs?" Lloyd R. Cohen, *Directions for the Disposition of My (and Your) Vital Organs*, 28 REGULATION 32, 38 (2005) [hereinafter Cohen, *Directions*]. Cohen suggests that a market in vital organs represents a reasonable balancing of human needs. *Id.* at 37. Favoring a market solution to the shortage of organs for transplantation, he has suggested an options or futures market, where

incentive to encourage cadaveric organ donation does not implicate the living donor organ commerce concerns underlying NOTA's prohibition on organ exchange.

A funeral benefit to cadaveric donor families does not involve a transaction where individuals or organizations profit from the sale of living donor organs for transplantation. The Pennsylvania program was purposely designed to provide only a limited amount of money, paid out of a state established trust fund.<sup>101</sup> Any expenditure from the trust fund could only be made to the funeral home and never directly to the donor's family, next of kin or estate.<sup>102</sup> The undesirable impropriety of payment associated with organ brokerage were basically eliminated due to the standard payment amount allocated through the controlled organ acquisition process, implemented by the organ procurement organization.<sup>103</sup> Under the Pennsylvania approach, no auctioning of cadaveric organs to the highest bidder could occur, a chief concern in NOTA.<sup>104</sup>

healthy individuals would have the opportunity to give an option on organs recovered at their death. Id. at 32. Individuals who die under appropriate conditions and have their organs recovered would be paid a previously determined sum to their estate or designee. Id. See also Cohen, supra note 25, at 32-36; Harris & Alcorn, supra note 30, at 232-33 (proposing a posthumous organ market regulated by the Food and Drug Administration where relatives would be permitted to sell the organs of decedents through private licensed brokers when the decedent has provided prior consent). Because policy makers are unlikely to implement a market in organs, Cohen has become a proponent of Lifesharers, a nonprofit organization functioning within the framework of NOTA, where members who indicate a willingness to donate their organs upon death through Lifesharers are given preference to an available organ of another member if ever in need of one. See Cohen, Directions, supra note 100, at 33; Hurley, supra note 1, at 135; Lifesharers, Lifesharers: Organs for Organ Donors, http://www.lifesharers.com (last visited Jan. 19, 2006). As of January 2006, 3,714 individuals had become members of Lifesharers and 23 were on a waiting list to Lifesharers, FAQ, http://www.lifesharers.com/faq.asp (last receive an organ. visited Jan. 19, 2006). No member of Lifesharers has yet to die in circumstances that would permit organ recovery. Id.

101. Ubel, *supra* note 7, at 207-08 ("Although the program theoretically could offer up to \$3,000 in benefits, the trust fund is unlikely to be large enough to offer more than \$1,000 any time soon."). The small amount was intended "to emphasize that it is only a token of appreciation, not a strong financial incentive." *Id.* 

102. 20 PA. CONST. STAT. § 8622 (2001).

103. Peters, supra note 83, at 1303.

104. Ubel, *supra* note 7, at 207–8. See also Joint Letter to Congress, supra note 32 (stating that it is crucial that a gift be of a set amount and given for patients who are judged to be good donor candidates to avoid "unseemly haggling").

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A funeral benefit incentive also does not compromise the health of the donor or organ recipient. The donor's health is not compromised because hospitals are unlikely to change the nature of care for dying patients.<sup>105</sup> Hospitals with non-heart-beating donor protocols are not permitted to discuss organ donation until family members have made the decision to withdraw their loved-ones from life-support.<sup>106</sup> A funeral benefit is also unlikely to compromise the quality of organs harvested and the lives of organ recipients, since cadaveric organ donation has stringent criteria that would not change because funeral benefits are paid.<sup>107</sup>

It is important to note that NOTA does not represent a policy which claims that it is unethical to engage in the buying and selling of human body parts, only that it is unethical to engage in the buying and selling of organs from living donors.<sup>108</sup> Individuals and organizations are permitted to legally engage in the buying and selling of body parts for medical and scientific research.<sup>109</sup> Brokerage in human body parts is

105. Ubel, supra note 7, at 208.

107. Peters, supra note 83, at 1304. See also Developments in the Law - Medical Technology and the Law: Organ Transplantation, 103 HARV. L. REV. 1614, 1625 (1990) (arguing that a market solution to the organ shortage does not result in poorer quality organs as did the commerce in blood).

[C]ommercial blood banks generally obtained their blood from populations that had a higher rate of hepatitis infection and, because of technological limitations, they could not effectively screen out infected donors. These limitations do not apply to screening potential organ donors because screening for inferior or infected tissue is relatively quick and inexpensive when the "cadaver lies exposed in the hospital treatment room."

*Id. See also* Robinson, supra note 93, at 1048-49; Harris & Alcorn, *supra* note 30, at 217 (pointing out that the problems with quality and safety of commercial blood have been resolved due to technological advances in screening). *But see* Goldberg, *supra* note 46 at A1 (noting the concern of Dr. Francis L. Delmonico, a Massachusetts General Hospital transplant surgeon, that "payments could 'undermine the integrity of the donor pool' and would give relatives incentives to cover up flaws in a potential donor's medical record to get the money").

108. Harris & Alcorn, *supra* note 30, at 213 (noting the thriving market for "blood, tissue, and human reproductive cells").

109. Robert Cohen, Body Trade: A Largely Unregulated Commerce in Organs and Tissues is Alarming Experts, BALT. SUN, Jan. 8, 2006, at 6F ("The law allows

<sup>106.</sup> *Id.* Non-heart-beating donors are patients who are "ventilator dependent but are not diagnosable as brain-dead." *Id.* When families request that ventilator support be withdrawn, such patients are then taken to an emergency room to have their organs procured. *Id.* 

also unregulated for non-research uses.<sup>110</sup> The permissibility of trading in human body parts underscores the notion that NOTA is primarily concerned with living donation and living donor welfare. Pennsylvania's funeral benefit sought to incentivize cadaveric organ donation, not living, and did not involve the substantial profiteering that is permitted in the brokerage of human body parts for research and other medical purposes.<sup>111</sup> Instead, the organs procured would sustain the life of another and the funeral benefit given for its donation would be carefully regulated, presenting no risk of compromising donor health.

#### A Funeral Benefit is not Exploitative, But Rather, Serves the Interest of Minorities Uniquely Burdened by the Organ Shortage

Within the concern over marketing in living donor organs, NOTAsponsors feared the buying and selling of human organs would result in exploitation of poor and vulnerable individuals.<sup>112</sup> The drafters feared that commerce in living donor organs would exploit or wrongfully propel individuals with financial difficulties to act against their best interest to benefit affluent individuals who could afford to pay for organs.<sup>113</sup> The wealthy would take advantage of the misfortune of the

111. Nonetheless, some critics object to the use of financial incentives for cadaveric donation merely on the notion that incentives undermine a respect for human mortal remains, and that some things "are simply not for sale." Gilbert Meilaender, 'Strip-mining' the Dead, NAT'L REV., Oct. 11, 1999, at 42, 43 ("To treat those mortal remains with respect, to refuse to see them as merely in service of other goods, is our last chance to honor the 'extraterritoriality' of each human life and to affirm that the human person is not simply a 'part' of a human community."). Id. at 44. However, one might respond to this critique by pointing out that organs obtained from a cadaveric donor are not merely in service of other goods, but in the service of providing life to another human being.

112. See NOTA Hearings, supra note 97.

113. See id. One way impoverished individuals presumably act against their interests is by underestimating the risk involved in the organ donation when under financial pressure. See also Calandrillo, supra note 84.

organizations and entrepreneurs to charge 'reasonable' acquisition and handling fees for processing, storing and transporting of body parts.").

<sup>110.</sup> Annie Cheney, *The Resurrection Men*, HARPER'S MAG., Mar. 2004, at 45, 47 (cadavers are sold for commercial seminars to demonstrate medical gadgetry and as raw material for a variety of surgical and cosmetic products). Corpses generally enter the supply chair for various uses through donations and are subsequently parceled out to middlemen. *Id.; see also* Cohen, *supra* note 109, at 6F (noting that the body trade takes in hundreds of millions of dollars each year).

poor.<sup>114</sup> Living donor organ sales arguably also would have a "perverse distributive impact" where disproportionately poor persons, and often minorities, would be persuaded to sell, and the wealthy primarily could afford to buy.<sup>115</sup> This scenario would result in a disproportionate allocation of organs among the rich and poor, and among minorities and non-minorities.<sup>116</sup> In essence, the fear was that if organs became marketable, the poor would suffer for the sake of the rich.

The NOTA-sponsors feared a for-profit market in living donor organs.<sup>117</sup> However, a funeral benefit incentive to increase cadaveric donation is a proposal of an entirely different nature. A funeral benefit does not raise the same exploitation concerns, as does an organ brokerage, for several important reasons. First, the rich are not more likely to receive an organ than the poor and donors (or donor families) are not prompted to act against their interest by compromising the health of their loved-ones. Second, a funeral benefit may particularly benefit African-Americans, a minority group that has historically experienced exploitation in the medical setting and which is currently disproportionately burdened by the organ shortage.<sup>118</sup>

A funeral benefit incentive to encourage cadaveric organ donation does not result in a NOTA-feared scenario where auctions would direct organs from poor living donors (possibly in developing nations) to the highest bidder.<sup>119</sup> With funeral benefit offerings, rich individuals in need of an organ would be no more likely than poor individuals to receive an organ, as allocation would depend on matching, time on the waiting list, and medical necessity.<sup>120</sup> Family members of limited financial means would also not be in the position of having to act

120. Peters, supra note 83, at 1303.

<sup>114.</sup> Wilkinson, *supra* note 92, at 130 (indicating that some ethicists characterize the exploitation in organ sales as the taking advantage of others' "comparatively limited range of viable options.").

<sup>115.</sup> Calandrillo, *supra* note 84, at 93.

<sup>116.</sup> *Id.* (noting that this concern could be more directly characterized as "distributive injustice;" however, distributive injustice is characterized as "exploitation" here because a market to procure and allocate organs (it is argued) disproportionately exploits the poor and minorities as a group by asking them to shoulder the burden of organ donation while distributing a disproportionate share of available organs to majority groups).

<sup>117.</sup> See Sten, supra note 90, at 216.

<sup>118.</sup> See Danovitch et al., supra note 6, at 905.

<sup>119.</sup> Ubel, *supra* note 7, at 208; *see also* Sten, *supra* note 90, at 219 (concluding that a funeral benefit in a form like Pennsylvania's "can exist within the accepted legal and ethical boundaries that govern the national organ system").

against their interests by making a decision that could compromise the health of a loved-one, simply to obtain the funeral benefit, since discussion about organ donation would only take place once a ventilator-withdrawal decision is made.<sup>121</sup> Rather than being exploitative, a funeral benefit actually remedies a present inequity present in the NOTA framework -- where hospitals, medical teams, and organ transplant providers are permitted to earn thousands of dollars for each organ transplantation, but families receive nothing for the deceased's donation.<sup>122</sup>

A funeral benefit incentive avoids the primary exploitation concerns underlying NOTA, but also may particularly benefit African-Americans, a minority group especially burdened by the shortage of organs.<sup>123</sup> Of the 58,000-plus Americans on the national waiting list for kidneys, thirty-six percent are African-American, three times their percentage in the general population.<sup>124</sup> African-Americans must wait more than twice as long to get kidneys than Caucasians.<sup>125</sup> The disparity in organ transplantation is due to a lack of matchable organs

123. Ubel, supra note 7, at 206; see also Orly Hazony, Increasing the Supply of Cadaver Organs for Transplantation: Recognizing that the Real Problem is Psychological Not Legal, 3 Health Matrix 219, 251-52 (1993)(noting that African Americans have much to gain from an increase in the supply of organs as they and are four times more likely to develop kidney disease than white Americans and represent thirty percent of dialysis patients in the U.S.).

124. Danovitch, supra note 6, at 905.

125. Laura Johannes, Delicate Surgery: In Kidney Quest, New Rules Boost Chances for Blacks; Reform Seeks to Close Gap in Transplant Wait Times; Worries About a Downside; Mr. Philips Clears Up Record, WALL ST. J., June 18, 2004, at A1 ("The median waiting time for blacks . . . is 4.7 years, compared with about 2.2 years for whites, according to figures for people who got on the list in 1998"). UNOS has recently changed the criteria by which organs are matched with recipients, allowing organs to go to individuals with mis-matched proteins, favoring African-Americans. Id. However, the new matching scheme potentially could result in more organ rejections. Id.

<sup>121.</sup> Ubel, supra note 7, at 208.

<sup>122.</sup> Calandrillo, *supra* note 84, at 115 (paraphrasing Peter Young, the author makes the point, "why do we allow hospitals, medical teams, and organ transplant service providers to make thousands of dollars from each organ donated, yet we do not permit the families of donors to receive a dime, even for burial costs."). *See also* Charles A. Erin & John Harris, *An Ethical Market in Human Organs*, 29 J. MED. ETHICS 137, 137 (2003)(noting the hypocrisy in the ethics of buying and selling organs and other body parts).

being procured for African-Americans.<sup>126</sup> Research suggests that African-Americans are less willing to donate a family member's organs.<sup>127</sup> Studies indicate that mistrust of the medical community is a prime reason for the refusal to donate; this mistrust stems from a fear of exploitation and a perception that African-American lives are devalued in the medical setting.<sup>128</sup>

Although African-Americans may be less inclined to donate their family members' organs, a survey on the use of financial remuneration for organ donation discovered that a significant number of African-Americans favored some form of payment to families who donate organs.<sup>129</sup> Such data suggest that many African-Americans would

127. Patrick McNamara et al., Correlates of Support for Organ Donation Among Three Ethnic Groups, 13 CLINICAL TRANSPLANTATION 45, 47 (1999). In a survey of 6080 respondents, only 22.6 percent of African-Americans reported that they were very willing to donate their organs after death as opposed to 42.9 percent of whites. *Id. See also* Siminoff & Saunders Sturm, *supra* note 123, at 62 ("Differences . . . in willingness to donate may be rooted in different attitudes toward the medical community, the importance or extent of intra-familial communication about organ donation, and the assumed altruistic basis of the organ procurement system.").

128. Siminoff & Saunders Sturm, supra note 126, at 64. The belief that African-Americans are devalued in the medical setting is rooted in the community's awareness of historical instances, such as the Tuskegee Syphilis Study, where unauthorized medical experimentation on African-Americans took place and continued disparities in the provision of medical care. Id. Research has revealed "if even one family member shows mistrust of the medical staff, it may be enough to derail donation." McNamara et al., supra note 127, at 48, 49. Two other significant factors that tended to discourage donation were a family's failure to discuss end of life issues and concerns about surgical disfigurement of a relative's body after donation. Id. See also Hazony, supra note 123, at 253 (noting that socioeconomic problems and distrust of the medical establishment are components of the low donation rate for blacks); Paul Delaney, Fighting Myths in a Bid to Get Blacks to Consider Transplants, N.Y. TIMES, Nov. 6, 1991, at C17 (reporting on research that suggests distrust in the medical establishment can result in African-Americans refusing to donate under a perception that there is discrimination in the selection of organ recipients and that other African-Americans will not benefit by the organ donation).

129. Siminoff & Sauders Sturm, *supra* note 126, at 68 (43.2 percent of African Americans favored payment whereas only 12.9 percent of whites were favorably disposed to payment). Other surveys suggest that favorability to compensation for organ donation is not just limited to African Americans, but extends to other

<sup>126.</sup> Laura A. Siminoff & Christina M. Saunders Sturm, African-American Reluctance to Donate: Beliefs and Attitudes about Organ Donation and Implications for Policy, 10 No.1 KENNEDY INST. ETHICS J. 59, 59-60 (2000).

respond to a financial incentive in the form of a funeral benefit, and the resulting increase in cadaveric organ donation among individuals in the African-American community could add years of life to the large number of African-Americans waiting for an organ transplant.<sup>130</sup>

A funeral benefit encouraging organ donation in the African-American community hardly can be characterized as exploitative in view of the organ needs and perceptions of many individuals within the African American community.<sup>131</sup> Not only would funeral benefits yield organs and bring life to the disproportionately high number of African-Americans on waiting lists, but it also would serve as a gesture on the part of the medical community (and society) to value the life of the deceased and deal with the family in a dignified way.

#### CONCLUSION

With over 90,000 individuals waiting for an organ transplant,<sup>132</sup> and the waiting list growing longer at twice the rate of the number of transplants,<sup>133</sup> the time is now for Congress to abandon the purely altruistic framework of organ donation under NOTA, and allow for

130. In view of the study's findings, the researchers conclude that valuation of altruism in the current organ procurement system at the expense of all other values is questionable and based upon values that reflect the attitudes of whites. Siminoff & Saunders Sturm, *supra* note 126, at 68.

131. It is significant to note that the Pennsylvania pilot program to offer a funeral benefit was passed in response to the organ shortage and, in particular, its adverse effect on African-Americans. Siegel, *supra* note 16, at 941. In fact, the drafter of the Pennsylvania legislation was Bill Robinson, a state representative whose constituents were primarily African-American. Ubel, *supra* note 7, at 206. Such background suggests that a funeral benefit to encourage cadaveric organ donation is perceived by policy makers as serving the interest of African Americans. Opponents of financial incentives counter this claim by contending that incentives directed primarily at the African-American community will prompt recollection of the "the past experience of 'commerce in bodies' that is unfortunately a part of our country's history." UNOS Report, supra note 60.

132. See United Network for Organ Sharing Online, http://www.unos.org (last visited Jan. 15, 2005).

133. See Port, supra note 4, at 843.

individuals in a general polling sample. A study by UNOS found that fifty-two percent of the individuals sampled favored some form of compensation for organ donation. UNOS Report, supra note 60. Another study by UNOS and the NKF found that forty-eight percent of the sample are in favor of compensation. Id. (individuals in favor of compensation in each of the studies tended to be male, younger, and of more modest income). See also Sanford & Rocchiccioli, supra note 8, at 278.

innovative alternatives to ascend to the status quo. Pennsylvania's funeral benefit incentive is such an innovation. Unfortunately, Pennsylvania's response to the crisis in organ transplantation has been inhibited by the ambiguity of federal law and by a policy that was not intended to reach the use of indirect incentives to encourage cadaveric organ donation.

Congress must respond by clarifying the NOTA provision banning the exchange of organs for valuable consideration, by indicating that valuable consideration does not include a reasonable financial benefit to the family members of cadaveric organ donors. Congress should also authorize demonstration projects to examine whether financial incentives would increase cadaveric organ donation.<sup>134</sup> By taking such actions, Congress can provide a path for the implementation of plans like Pennsylvania's novel funeral benefit encouraging cadaveric organ donation, a plan that enhances the ability of families to honor the lives of the deceased and helps save the lives of many in need of an organ transplant.

<sup>134.</sup> See Arthers, supra note 20, at 1128–29 (arguing that policies favoring cadaveric organ donation are preferable to policies favoring living donation as cadaveric donation is of lesser cost and greater potential benefit); Siegel, supra note 16, at 952 (suggesting that the best way to address the immediate organ shortage is to administer pilot programs providing incentives for organ donation as Pennsylvania has sought to do); Sten, supra note 90, at 219 (recommending the use of a death benefit as it can exist within the accepted legal and ethical boundaries that govern the national organ system).