# CONFRONTING THE LIMITS OF ALTRUISM: A RESPONSE TO JAKE LINFORD

# MICHELE GOODWIN\*

For nearly two and a half decades an organ transplant bubble has persisted under the neglectful gaze of federal legislators. The neglect—not an absence of attention altogether—but rather, a myopic strain to see anything other than what seemed to be the right vision for transplantation in 1984, dominates contemporary legislative response. In 1984, Congress enacted the National Organ Transplant Act (NOTA),<sup>1</sup> a sweeping response to the calculated misdealing of a self-described organ broker. One could easily appreciate Congressional intervention in the scheme concocted by Barry Jacobs,<sup>2</sup> a Virginia doctor who, after losing his license to practice medicine, decided to obtain organs from the poor to give to the rich—a sort of reverse Robin Hood effort.<sup>3</sup>

3. NOTA provided a uniform response to all fifty states. Virginia, the location of Jacobs' firm, was the first state to outlaw the sale of organs and other states swiftly followed. MUNSON, supra note 2, at 111; see, e.g., VA. CODE ANN. § 32.1-291.16 (Supp. 2008) (stating that it is unlawful to sell, or buy body parts); CAL. PENAL CODE § 367f (West 1999) (stating that it shall be unlawful to receive, sell or promote the transfer of human organs); MD.

<sup>\*</sup> Everett Fraser Professor of Law and Professor of Medicine and Public Health, University of Minnesota Law School.

<sup>1.</sup> National Organ Transplant Act, 42 U.S.C § 273 (2000). The Organ Procurement Transplantation Network was established by 42 U.S.C. § 274 (a)-(b) (2000).

<sup>2.</sup> Dr. Barry Jacobs' 1983 proposal to broker kidneys for a fee and commission attracted strident criticism and media coverage. His was not the first entrepreneurial effort to broker or sell organs, however it appeared to be the most organized—with a business plan and targeted donors. Politicians responded quickly to the hysteria caused by Jacobs' plan. Under his proposal Medicare or Medicaid would reimburse organ costs; otherwise, the recipient would pay a fee ranging from \$2,000 to \$5,000 for his services and a set price for the organ. Among those targeted by his proposal were people of color or third world indigents, who for nominal compensation were expected to provide kidneys for wealthier Americans. See National Organ Transplant Act: Hearings on H.R. 4080 Before the Subcomm. on Health and the Environment of the H. Comm. on Energy and Commerce, 98th Cong., 245-46 (1983) (testimony of Barry Jacobs, M.D., Medical Director, Int'l Kidney Exchange, Ltd.); Ellen Goodman, Life for Sale, WASH. POST, Oct. 1, 1983, at A15 (discussing how Dr. Barry Jacobs set up a business to broker and sell human kidneys); RONALD MUNSON, RAISING THE DEAD: ORGAN TRANSPLANTS, ETHICS, AND SOCIETY 109-10 (2002) (discussing Dr. Barry Jacobs and his effort to establish an international kidney exchange program).

As with most swift legislative action, particularly near an election cycle, mistakes and excessive platitudes are folded into the process sometimes resulting in "cause legislation." In the instant case, Congress undertook a sweeping reform to ensure that organs and body parts would never be traded for cash or any other economic, spiritual, or emotional value. Their cause was not only to issue a stern warning to those like Dr. Jacobs, but also to stamp out any possibility that organ donations would be anything other than blind, emotionally-neutral, altruistic exchanges. At the time, this legislative approach may have seemed like the morally upstanding thing to do. Who could argue against a platform that protected poor people's bodies from the rich and greedy?

By enacting Section 301 of NOTA, Congress placed into law an incredibly broad protocol that specifically prohibits "valuable consideration" in organ exchanges. These two words upended state organ transplant laws<sup>4</sup> that were enacted long before the federal government intervened, and made it a crime (punishable by fine and incarceration) to provide any actual or symbolic remuneration.<sup>5</sup> According to Richard Epstein, "[w]ith that prohibition, NOTA has enshrined altruism as the watchword of the transplantation establishment."<sup>6</sup>

As with other cause legislation, the morally expedient response may not be the best legal or ethical answer to the larger social problem. In essence, Congress undertook crafting legislative policy in response to one rogue doctor.<sup>7</sup> The result offered a streamlined, new approach to organ transplant

CODE ANN., HEALTH-GEN. § 5-408 (LexisNexis 2005) (stating that a person may not sell or buy any body part); N.Y. PUB. HEALTH LAW § 4307 (McKinney Supp. 2009) (stating that it is unlawful to acquire or receive consideration for any human organ for transplantation); MICH. COMP. LAWS SERV. § 333.10204 (LexisNexis 2005) (stating that no person shall acquire or receive consideration for the purpose of transplantation).

The National Conference of Commissioners on Uniform State Laws (NCCUSL) drafted the Uniform Anatomical Gift Act (UAGA) in 1968, nearly two decades prior to the first federal legislation on organ transplantation. See, e.g., REV. UNIF. ANATOMICAL GIFT ACT, 8A U.L.A.
(Supp. 2008) [hereinafter UAGA] (noting that the laws among states are no longer uniform, and that the federal government has been active in organ transplantation issues).

<sup>5. 42</sup> U.S.C. § 274e(b) (2000).

<sup>6.</sup> Richard A. Epstein, Altruism and Valuable Consideration in Organ Transplantation, in WHEN ALTRUISM ISN'T ENOUGH: THE CASE FOR COMPENSATING KIDNEY DONORS 79, 79 (Sally Satel ed., 2008).

<sup>7.</sup> The medical community is not unfamiliar with this type of legislation, which in recent years was best captured by the Terri Schiavo case. See George J. Annas, *Health Care Reform in America: Beyond Ideology*, 5 IND. HEALTH L. REV. 441, 456 (2008) (discussing the symbolism of the Terri Schiavo case and its impact on Congress and the medical community as a whole); Shannon L. Pedersen, Comment, *When Congress Practices Medicine: How Congressional Legislation of Medical Judgment May Infringe a Fundamental Right*, 24 Touro L. Rev. 791, 802 (2008) ("For example, in 2005 Congress passed emergency legislation applying only to a single person in an attempt to direct her medical treatment.").

policy in the United States, but hidden within the new organ agenda was a symbolism so severe that it undermined state autonomy and crippled the flexibility of organ exchanges for time to come.<sup>8</sup> What Congress ignored in its swift pursuit of the fraudulent doctor was the more important and persistent problem: the need for greater organ supply. Wrongfully assumed was that organ transplantation was only about protecting the poor from the wealthy.<sup>9</sup> The more significant issue—and why Barry Jacobs was only a mild threat—is that there are too few altruistic donations to meet transplant demand.<sup>10</sup>

The central challenge for organ transplant patients is how to stay alive while waiting for an organ that may never materialize. More than 100,000 Americans are now on transplant waitlists.<sup>11</sup> According to Dr. Benjamin Hippen, the wait time for an organ is approaching ten years.<sup>12</sup> For most patients, including those on dialysis, ten years is a "death sentence."<sup>13</sup>

10. The total number of living donors between January and November 2008 was 5,620, compared with 20,008 deceased donors. ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK, DATA at http://optn.org/data (last visited Apr. 19, 2009) [hereinafter OPTN]. See also MICHELE GOODWIN, BLACK MARKETS: THE SUPPLY AND DEMAND OF BODY PARTS 37 (2006) (explaining that altruism cannot resolve the shortage of organs that currently exists in America) [hereinafter GOODWIN, BLACK MARKETS].

11. OPTN, supra note 10.

12. Satel, supra note 8, at 3; Audio mp3: Benjamin Hippen, Organ Sales and Moral Travails: Lessons from the Living Kidney Vendor Program in Iran, *at* www.law.uchicago.edu/Lawecon/events/commodities/av.html (last visited Apr. 19, 2009).

13. Goodwin, The Body Market, supra note 9, at 615; see Rebecca D. Williams, Living Day-to-Day with Kidney Dialysis: Quality Improvements Continue for Devices and Clinics, FDA CONSUMER, Jan.-Feb. 1998, at www.fda.gov/FDAC/features/1998/198\_dial.html (last visited Apr. 19, 2009) (noting that after ten years on dialysis, the survival rate is approximately ten percent); UNITED STATES RENAL DATA SYSTEM, 2008 USRDS ANNUAL DATA REPORT: PATIENT SURVIVAL 244 (2008), available at www.usrds.org/2008/ref/l\_Patient\_Survival\_08.pdf (last visited Apr. 19, 2009) (reporting that the unadjusted ten year survival probabilities for dialysis patients was 10.3 in 1996). Rationing plays a significant (although sometimes underestimated) role in the organ transplant regime. As a result, tens of thousands of patients are on dialysis, but only a percentage of those are ever referred to the organ transplant waitlists. In John F. Kilner's study of 453 dialysis and transplant center medical directors, he found that a variety of non-medical criteria were considered in the transplantation and dialysis referral or decision-making processes. Kilner, an ethicist who worked at the Park Ridge Center for Study of

<sup>8.</sup> See Sally Satel, Introduction to WHEN ALTRUISM ISN'T ENOUGH: THE CASE FOR COMPENSATING KIDNEY DONORS 1, 9 (Sally Satel ed., 2008) (noting that the federal prohibition against buying and selling organs might one day need to be changed to address the organ shortage and give states the power to implement their own ways of regulating organ donation).

<sup>9.</sup> See generally Michele Goodwin, The Body Market: Race Politics & Private Ordering, 49 ARIZ. L. REV. 599, 625 (2007) (arguing that other concerns about organ transplantation are the need for a greater supply of organs and the use of race card politics to undermine potential transplant-procurement alternatives) [hereinafter Goodwin, The Body Market].

According to a report issued by the National Institutes of Health, the upper range of survival for the lowest risk dialysis patients is 1,245 days, which is less than three and a half years.<sup>14</sup> According to that same study, those in the highest category of risk can expect to survive while on dialysis less than a year and a half.<sup>15</sup>

More than 6,500 patients on the waitlist will die this year.<sup>16</sup> Others will suffer the consequences of a nefarious form of rationing—they will be kicked off the list. Unaccounted for are the thousands of patients suffering from organ failure that never make it onto the waitlist. Most of those patients are tethered to dialysis machines several days per week, a few hours at a time.<sup>17</sup> For them, there is no such thing as a family vacation, honeymoon, hiking, or camping trip; their lives are geographically confined to the radius of a dialysis center. And yet, most patients—even those receiving dialysis treatments—will not survive beyond five to six years after being diagnosed with end stage renal failure. Those dialysis patients with the greatest chances of surviving up to five years are likely to be part of a cohort receiving treatments five to seven times per week.<sup>18</sup>

Deciding the best way forward has more recently consumed a group of medical and legal scholars advocating for a change in organ transplant

15. See *id*. ("Median survival in the decile ranked at highest risk was 451 days using the FULL model versus 524 days using the BASE model.").

16. See OPTN, U.S. Transplant Waiting List Passes 100,000 at http://optn.transplant. hrsa.gov/news/newsDetail.asp?id=1165 (last visited Apr. 19, 2009) (noting that both active and inactive candidates who died waiting a transplantation was nearly 6,700 in 2007, and also that reported deaths on the transplant waiting list have decreased each year since 2004).

17. See generally LAURIE KAYE ABRAHAM, MAMA MIGHT BE BETTER OFF DEAD: THE FAILURE OF HEALTH CARE IN URBAN AMERICA 39 (1993) (following a patient who spends approximately six hours a day, including travel, waiting, and treatment time, three days a week on dialysis).

18. See Marlene Busko, Survival Better with Short, Daily Dialysis than with Conventional Hemodialysis, MEDSCAPE MED. NEWS, Dec. 13, 2006, at www.medscape.com/viewarticle/ 549264 (on file with author) (summarizing results from Christopher R. Blagg et al., Comparison of Survival Between Short-Daily Hemodialysis and Conventional Hemodialysis Using the Standardized Mortality Ratio, 10 HEMODIALYSIS INT'L 371 passim (2006)).

Health, Faith, and Ethics in Chicago, observed that physician decisions were shaped by a variety of factors that included a patient's psychological stability, their family's financial and emotional support, scientific knowledge gained by treating them, and even how much society benefits if they live. Barbara Noah referred to this practice as a pernicious type of rationing that ultimately favors the elite over the poor when limited transplant opportunities are available. John F. Kilner, Selecting Patients When Resources Are Limited: A Study of US Medical Directors of Kidney Dialysis and Transplantation Facilities, 78 AM. J. PUB. HEALTH 144 passim (1988).

<sup>14.</sup> See Douglas E. Mesler et al., How Much Better Can We Predict Dialysis Patient Survival Using Clinical Data?, 34 HEALTH SERVICES RES. 365, 371 (1999) ("Using the BASE model, the average observed median survival in the 50 percent at least risk was 1,130 days versus 1,245 days using the FULL model.").

policy.<sup>19</sup> At the center of their "movement" of sorts, is the attempt to push beyond the swollen door of altruism. They argue that the rigid proscriptions in NOTA undermine patient care, thwart state autonomy, crowd out generous individuals who want to donate, but are economically constrained to do so, and reduces confidence in the U.S. transplantation system. These scholars have taken to crafting unique essays and proposals that offer economic models for organ incentives and critique the anti-commoditization position, while promoting incentive based programs.<sup>20</sup>

On a spectrum, new organ procurement proposals range from the innocuous and uncontroversial to the bold, daring, and unfeasible. Somewhere in the middle is the project crafted by Jake Linford, a University of Chicago Law School graduate, steeped in the philosophy of law and economics, and balanced by a commitment to altruistic principles and meanings. In his novel proposal to incentivize organ donation by providing college scholarships, Linford introduces a significant challenge.<sup>21</sup> Economists might read his proposal as being the weaker cousin to a bolder proposal that refuses to tether organ exchanges with anything other than pure financial reward: cash. On the whole, they would be right. Neither, however, does Linford's proposal win him friends from the altruistic

<sup>19.</sup> An unlikely coalition of economists, law professors, doctors, and scholars at thinktanks have taken up this issue. Their elastic task force (of sorts) includes this author, Sally Satel, Benjamin Hippen, Arthur Matas, Richard Epstein, Robert Montgomery, and Mary Simmerling, among others. See Jim Warren, Xenotransplant News: New Organization Formed with the Goal of Overcoming Resistance to a Trial of Financial Incentives to Increase Donation, 14 XENOTRANSPLANTATION 557, 560 (2007) (noting that a new organization named the American Organ Coalition was created "with the goal of increasing the number of organ donors in the [United States] by removing disincentives to donate.").

<sup>20.</sup> James Stacey Taylor & Mary C. Simmerling, Donor Compensation Without Exploitation, in WHEN ALTRUISM ISN'T ENOUGH: THE CASE FOR COMPENSATING KIDNEY DONORS 50, 52 (Sally Satel ed., 2008); Sally Satel, Death's Waiting List, N.Y. TIMES, May 15, 2006, at www.nytimes.com/2006/05/15/opinion/15satel.html (last visited Apr. 19, 2009); Michele Goodwin, The Organ Donor Taboo, FORBES, Oct. 15, 2007, at 32; Richard A. Epstein, The Human and Economic Dimensions of Altruism: The Case of Organ Transplantation, 37 J. LEGAL STUD. 459, 465 (2008); Gary S. Becker & Julio Jorge Elías, Introducing Incentives in the Market for Live and Cadaveric Organ Donations 1-2 (unpublished manuscript), available at http://home.uchicago.edu/~gbecker/MarketforLiveandCadavericOrganDonations\_Becker\_Elias.pdf (last visited Apr. 19, 2009); Arthur J. Matas, A Gift of Life Deserves Compensation: How to Increase Living Kidney Donation with Realistic Incentives, POL'Y ANALYSIS (CATO Inst.), Nov. 7, 2007, at 1, 1.

<sup>21.</sup> Jake Linford, The Kidney Donor Scholarship Act: How College Scholarships Can Provide Financial Incentives for Kidney Donations While Preserving Altruistic Meaning, 2 ST. LOUIS U. J. HEALTH L. & POL'Y 265 (2009).

community that believe organs should never be surrendered for value of any kind.<sup>22</sup>

Linford and I start from a similar understanding of the underlying factual issues in supply and demand. In this Essay, I shall only briefly offer what some of those facts look like from the bottom up as his Article provides a clear, engaged view of demand dynamics. I share his skepticism about whether the stagnant organ procurement system can retool and jumpstart itself without a bold shift in federal policy. Linford is acutely aware that any efforts to offer a dignified alternative to our currently lacking organ donation system will require not only a legal, but also a socio-political response. I and others welcome these keen insights. The differences we share are not in the background presumptions, but rather in how much of the baggage from prior commitments must be brought into the "model" future of organ transplantation.

Specifically, we differ on how to value altruism. I am more skeptical about what altruism means (beyond its symbolism) and how it translates into this sphere, and thus find its value in incentive based and non-incentive based organ procurement programs negligible at the ground level and corruptible at a higher level. Altruism is a seductive concept that makes the idea of taking an organ from one and implanting it in another far more palatable. The problem with platforms that attempt to gain legitimacy by way of promoting altruism is that they concede that altruistic donation is the sole legitimate platform for organ procurement. Clearly this cannot be correct. Yet, it remains a deeply entrenched perspective. Under this view, all other procurement programs must pass the altruism meter, lest they be considered unethical and immoral. However, bounded in altruism are problematic behaviors, choices, and consequences that on inspection are quite *un*-altruistic!<sup>23</sup>

<sup>22.</sup> See MARGARET JANE RADIN, CONTESTED COMMODITIES 125-26 (1996) (arguing that organ-selling threatens personhood); Francis L. Delmonico & Nancy Scheper-Hughes, Why We Should Not Pay for Human Organs, 38 ZYGON J. OF RELIGION & SCIENCE 689, 696-97 (2003) (arguing that "[t]he division of the world into organ buyers and organ sellers is a medical, social, and moral tragedy of immense and not yet fully recognized proportions.").

<sup>23.</sup> Early efforts to bring dialysis to sick kidney patients were facilitated by altruistic committees and medical boards. One infamous organization, the Seattle "God Squad," was charged with the task of determining who qualified for this beneficial treatment. Their aim was surely altruistic, but the implementation was undeniably discriminatory. The committee rejected the unemployed, divorcees, and alcoholics. The "God Squad" scrutinized with some severity those who seemed to lack "social worth." This group included kidney patients who lacked formal education and others who were less mobile. See Albert R. Jonsen, The God Squad and the Origins of Transplantation Ethics and Policy, 35 J.L. MED. & ETHICS 238, 238 (2007) (observing that the admissions and policy committee of the Seattle Artificial Kidney Center was nicknamed the "God Squad"); see generally David Sanders & Jesse Dukeminier, Jr., Medical Advance and Legal Lag: Hemodialysis and Kidney Transplantation, 15 UCLA L.

More importantly, altruism does not resolve organ demand. In the two decades since the passage of NOTA, the transplant-donation gap has widened so severely that claims of Americans engaged in black market trades in organs can no longer be dismissed.<sup>24</sup> Thus, Linford's attention to altruism makes sense on one hand, but handicaps his proposal on another. His astute thinking about the "tipping point" in organ transplantation must surely rest on a political calculation. In other words, any legislative agendas offering an alternative to exclusively relying on altruism must acknowledge the political landmines associated with incentives.

Legislators are concerned about the thirty second or one minute sound bites. To be certain, no Congressional leader wishes to be lampooned or mischaracterized as a sordid organ broker. Thus, crafting a palatable organ plan must remain a prime objective. And yet, the danger of appealing too fervently to the cause of altruism has the potential to offer a revisionist view of progress under an altruist regime.

On balance, Linford offers a timely challenge to current transplant policy, and his proposal is quite sensible. He provides a methodical, pragmatic, response to organ shortages; he is clearly aware that any attempts to reshape transplant policy in the U.S. means winning over the lackadaisical, and two decades of dormancy on transplantation policy demonstrates how difficult a challenge lies ahead.

This Essay responds to his proposal. Part I provides a brief empirical overview of organ transplantation in the U.S., uncovering the often hidden costs of altruism. Part II addresses the limits of altruism; it offers an approach grounded in socio-legal realism. Part III responds to the scholarship proposal set out by Linford. Part IV concludes this Essay.

REV. 357, 378 (1968) (observing that "[t]he Pacific Northwest is no place for a Henry David Thoreau with bad kidneys.").

<sup>24.</sup> GOODWIN, BLACK MARKETS, supra note 10, at 10-11; Nancy Scheper-Hughes, Organ Selling, Organ Theft, in THE NASTY SIDE OF ORGAN TRANSPLANTING (Norm Barber ed., 2007), at www.geocities.com/organdonate/organsellingorgantheft.html (last visited Apr. 19, 2009). For a discussion of black market organ trades in other countries, see generally Nancy Scheper-Hughes, Postmodern Cannibalism?: Organ Transplants in the Globalocal Market, WHOLE EARTH, Summer 2000, at 16 passim (discussing the international scope of the market in human organs); Jane Macartney, China to 'Tidy Up' Trade in Executed Prisoners' Organs, TIMES (U.K.), Dec. 3, 2005, at 48 (reporting on how the organs of executed prisoners in China were sold to foreigners for transplantation purposes); Jill McGivering, China 'Selling Prisoners' Organs', BBC NEWS, Apr. 19, 2006, at http://news.bbc.co.uk/2/hi/asia-pacific/4921116.stm (last visited Apr. 19, 2009) (noting that organs from thousands of executed prisoners in China are being sold for transplantation without consent).

## PART I: THE CURRENT SYSTEM

As of May 12, 2009, more than 100,000 people wait for organs in the U.S.<sup>25</sup> Over 7,000 of those patients will die within the 2009-2010 calendar year.<sup>26</sup> Others will be dismissed from the list because of age and the severity of their illnesses.<sup>27</sup> Rationing in this case means the healthiest are offered the better opportunities to become well. Only twenty percent of waitlist patients are likely to be transplanted and approximately 90,000 patients will roll over to the 2010 waitlist.<sup>28</sup>

Of the patients in line for organs, most need kidneys.<sup>29</sup> In fact, three quarters of the transplant waitlist consists of patients needing kidneys. At the end of February 2009, there were 83,447 registrants waiting for kidneys.<sup>30</sup> But that number tells us less than what we really need to know. For example, that figure undercounts the actual number of patients that would benefit from a kidney transplant, because it does not account for the 485,000 Americans with end-stage renal disease, or the more than 341,000 who are on dialysis, those who are registered on Internet websites, like *matchingdonor.com*, or those who decided that the black market might be far more expedient than waiting in the U.S. To be sure, the gains in organ donation pale in comparison with the number of registered patients who can expect to die before ever receiving a transplant.

Those generally opposed to organ incentives, including the type proposed by Linford, often complain that the poor and minority will ultimately become the victims of such proposals.<sup>31</sup> Among the concerns

<sup>25.</sup> UNITED NETWORK FOR ORGAN SHARING, ORGAN DONATION AND TRANSPLANTATION DATA, at http://unos.org (last visited May 12, 2009).

<sup>26.</sup> See OPTN, REMOVAL REASONS BY YEAR, at www.optn.org/latestData/step2.asp (choose category "Waiting List Removals"; then follow "Removal Reasons by Year" hyperlink) (last visited Apr. 19, 2009) (showing that from 2001-2007, over 7,000 people were removed from organ donor waitlists each year because of patient deaths).

<sup>27.</sup> Id.

<sup>28.</sup> See OPTN, TRANSPLANTS BY DONOR TYPE, at www.optn.org/latestData/step2.asp (choose category "Transplant"; then follow "Transplants by Donor Type" hyperlink) (last visited Apr. 19, 2009) (From 2003-2008, there were at least 25,000 organ transplants in the U.S. each year. With a current 2009 transplant waitlist count of over 100,000 patients, roughly 25,000 (25% of patients) are likely to be transplanted and roughly 75,000 (75% of patients) will roll over to the 2010 waitlist.).

<sup>29.</sup> OPTN, CURRENT U.S. WAITLIST, OVERALL BY ORGAN, at www.optn.org/latestData/ step2.asp (choose category "Waiting List"; then follow "Overall by Organ" hyperlink) (last visited Apr. 19, 2009).

<sup>30.</sup> Id.

<sup>31.</sup> ARTHUR L. CAPLAN, AM I MY BROTHER'S KEEPER? 95-96 (1997); Rick Weiss, A Look at . . . The Body Shop: At the Heart of an Uneasy Commerce, WASH. POST, June 27, 1999, at B03 ("Rather than reducing disparities between the rich and the poor, compensation for

voiced are that the poor are less sophisticated and more susceptible to coercion.<sup>32</sup> The picture painted is one of powerlessness. In essence, opponents of organ incentives fear that people of color will become suppliers to wealthier, white Americans. They are slightly right, but mostly wrong. Here's why.

One third of kidney patients happen to be African-American.<sup>33</sup> In the current altruistic procurement regime, they wait longer for kidneys than all other ethnic groups.<sup>34</sup> Their extended waits are directly linked to severe secondary problems. African-Americans, for example, suffer the highest death rates among all groups while waiting for a kidney, and are passed over more frequently.<sup>35</sup> So, while it is true that the poor might be more induced than wealthier counterparts to part with a resource in order to gain an alternative value (cash, home, an education, etc.), it is also true that more kidneys are needed to save the lives of African-Americans.

The critical issue here is that demand has not plateaued. Instead, the kidney waitlist more than doubled over the past ten years and nearly tripled in the last thirteen years.<sup>36</sup> In 1994, just over 25,000 Americans were registered on the kidney waitlist, ten years later, the waitlist more than doubled to 54,231.<sup>37</sup> The increase in waitlist registrants brought about other externalities, including expanded waiting times.<sup>38</sup>

34. See OPTN, OPTN/SRTR 2007 ANNUAL REPORT 5-11 (2007), available at http://optn.transplant.hrsa.gov/data/annualReport.asp (follow "Download 2007 Annual Report" hyperlink) (last visited Apr. 19, 2009) (showing that African-American registrants waited on average more than any other ethnic group to receive a transplantable organ) [hereinafter OPTN 2007 ANNUAL REPORT].

35. GOODWIN, BLACK MARKETS, supra note 10, at 43-45; see also Barbara A. Noah, Racial Disparities in the Delivery of Health Care, 35 SAN DIEGO L. REV. 135, 136-37 (1998) (arguing that "[t]he role that conscious or unconscious racial bias may play in the health care context has, by comparison, attracted comparatively little public attention . . . " Specifically, Noah refers to organ allocation in the U.S. as a "pernicious" form of rationing that disserves blacks and other minorities.).

36. See OPTN, OPTN/SRTR 2004 ANNUAL REPORT 5-1 (2004), available at http://optn.transplant.hrsa.gov/data/annualReport.asp (follow "Download 2004 Annual Report" hyperlink) (last visited Apr. 19, 2009) (showing the waitlist in 1994 was 25,827, but increased to 54,231 in 2003) [hereinafter OPTN 2004 ANNUAL REPORT].

37. *Id.* The number of women on the waitlist went from 11,021 to 23,035 during the years 1994 through 2003. For men also, the waitlist increased dramatically. Note that in 1994, there were 14,806 men on the waitlist, making up 57.3% of those on the list. While

organs might exacerbate the differences, turning the poor into surgical ward slaves or feudal donors for the rich.").

<sup>32.</sup> CAPLAN, supra note 31, at 95-100.

<sup>33.</sup> OPTN, CURRENT U.S. WAITING LIST, ORGAN BY ETHNICITY, at www.optn.org/latestData/ step2.asp (choose category "Waiting List"; then follow "Organ by Ethnicity" hyperlink) (last visited Apr. 19, 2009).

Altruism proponents point to the fact that more kidneys are donated today than ever before, but such claims must be understood in context. In 1996, there were 9,200 organ donors, and in 2006, there were 14,756.<sup>39</sup> These snapshots offer a sterile view of organ donation, and must also be understood in context: lives were saved. Nonetheless, those donations serviced only a fraction of the waitlist. Moreover, increases in organ supply during that period can largely be attributed to the increase in living donors joining the organ supply pool in the past seven years. Consider, for example, that from 1999 to 2004, living donors either surpassed or very closely kept pace with cadaveric donors.<sup>40</sup> In essence, a power more nuanced and persuasive than blind altruism was at hand.

Kidneys provide the obvious case for testing new procurement regimes, precisely because they are the site of greatest demand, but also, the point of tremendous flexibility. Nature has provided an oversupply of kidneys per human body, leaving most of the population with one to spare or contribute to another. Thus, it comes as little surprise that Richard Epstein, Gary Becker, Cass Sunstein, and newer voices, including Jake Linford and Nevin Gewertz, generally focus their attention on increasing the kidney supply, and that the most persuasive platforms for organ incentives use kidneys as the central feature of their models.

#### PART II: ALTRUISM'S LIMITS

Ten years after the enactment of NOTA, organ donations in Italy tripled. In 1994, California tourists, Maggie and Reg Green donated their sevenyear-old son's organs, following his murder during a family excursion.<sup>41</sup> In honor of their benevolence, hospitals, events, schools, and streets in Italy were named for their son, Nicholas Green.<sup>42</sup> According to the family, they are overwhelmed by "the Nicholas effect"—that their generosity has had such a tremendous affect on the public surprised the couple and the transplant community.<sup>43</sup> The Greens' blind giving, particularly after their incredible tragedy, is perhaps one of the best examples of donation as a selfless, noble act. The Greens' generosity extended altruism's reach beyond their home community. For years, those who favor altruistic

the male to female ratio remained constant, the overall number of men on the waitlist increased to 31,196. *Id.* at 5-2.

<sup>38.</sup> See *Id.* at 1-6 (showing that the average number of days a registrant spends on the waitlist has increased dramatically since 1994).

<sup>39.</sup> Id. at 1-1; OPTN 2007 ANNUAL REPORT, supra note 34, at 1-1.

<sup>40.</sup> OPTN 2007 ANNUAL REPORT, supra note 34, at 1-1.

<sup>41.</sup> Reg Green, A Child's Legacy of Love, L.A. TIMES, May 15, 2002, at E2.

<sup>42.</sup> Id.

<sup>43.</sup> The Nicholas Green Foundation, at www.nicholasgreen.org (last visited Apr. 19, 2009).

2009]

donation have offered the compelling story of the Greens as evidence that altruism works.

Who could deny the statistics coming forth from Italy hailing the virtues of altruism? And yet, applying that unique story to other demographic spaces around the globe, most particularly the U.S., would undoubtedly produce different results. This assessment is hardly cynical; it is based on our common law tradition and social expectations. It is based on what we know.

Within the living donor context, more donations materialize in some years than through the purely blind altruistic process. In that context, timing, guilt, anguish, and family relationships may influence the donation process more often than not and more profoundly than acknowledged. Altruism at times may be driven by coercion, pressure, fear, and guilt. The emotional impact of an organ demand is difficult to quantify and may never be expressed in deference to the sick requestor. This blind spot exposes a significant weakness in the pro-altruism platform. In a few cases, however, we are offered a glimpse of the emotional drama that lurks beneath the gilded frame of altruism.

McFall v. Shimp and Curran v. Bosze offer some context; I offer them here as an aide memoire on the limits and emotional complexities of altruism. Both cases took up the question whether altruism can be compelled. What we learn from them is that intimacy, even the connection through family may not override the presumption of autonomy. Nor is intimacy sufficient—in the U.S.—to overcome a reluctance to donate organs and bone marrow. More instructive were the courts' pronouncements about the socio-legal history of the U.S., which provides a clearer picture why altruism has its limits.

# A. McFall v. Shimp

In the McFall case, a court considered whether a dying man, Robert McFall, who suffered from a rare bone marrow disease, could legally compel his cousin Shimp to donate bone marrow.<sup>44</sup> Other attempts to prevail upon Shimp failed; the lawsuit was McFall's last hope. McFall's survival was unlikely absent a bone marrow transplant from a suitable donor. After an arduous search, it was determined that only the defendant, his cousin Shimp, was a suitable donor. The cousin refused. In a barrage that included chiding Shimp for his selfishness, lack of moral stature, and indefensible decision, the court concluded that he owed nothing to his cousin.<sup>45</sup>

<sup>44.</sup> McFall v. Shimp, 10 Pa. D. & C.3d 90, 90 (1978).

<sup>45.</sup> Id. at 91-92.

Bone marrow is renewable; it regenerates within the body, and the success rates for donors and recipients are very high. Doctors at the time predicted that the bone marrow transplant could have saved McFall's life. It was also clear that Shimp was the last hope—the only member of McFall's family that matched. According to court and media records, the two were good friends as well as cousins; they hiked, fished, and spent time together as children. Despite that intimate relationship and the fact that a life could be saved, the law was not on McFall's side—at least not in the U.S. What then, are we to take away from this case?

The difficulty for McFall was in finding any U.S. precedent to support his case. He drew the court's attention to a 700 year old statute, citing King Edward I, 81 Westminster 2, 13 Ed. I, c. 24. His petition argued that in order to preserve or save the life of another, a society has the right to infringe upon an individual's right to "bodily security.'"<sup>46</sup> McFall's reach across the centuries and Atlantic Ocean was revealing as much for what it said about American culture as its reaffirmation of U.S. legal principles. Though sympathetic, Judge Flaherty offered a clear rebuttal grounded in American socio-legal history. To him, first principles necessarily mean "respect for the individual, and that society and government exist to protect the individual from being invaded and hurt by another."<sup>47</sup>

In short, Flaherty expressed that McFall's plea did not reflect the spirit or values of American jurisprudence. What he exposed was the coercive effect behind altruism—as McFall was not offering a payment—he simply wanted, albeit demanded a gift. According to the court, "[t]he common law has consistently held to a rule which provides that one human being is under no legal compulsion to give aid or to take action to save another human being or to rescue . . . [f]or our law to compel defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded."<sup>48</sup> Would the court's injunction have defeated the sanctity of the individual or promoted it? These are the costs and benefits some might suggest of living in a "free society."

### B. Curran v. Bosze

In Curran v. Bosze, the Illinois Supreme Court followed the same line of jurisprudence extolled in *McFall*, opining that an individual's altruism cannot be legally compelled by a relative.<sup>49</sup> Although this line of jurisprudence does not consider whether the legislature may legally compel forced-

<sup>46.</sup> Id. at 91.

<sup>47.</sup> Id.

<sup>48.</sup> Id. (emphasis added).

<sup>49.</sup> Curran v. Bosze, 566 N.E.2d 1319, 1345 (III. 1990).

2009]

CONFRONTING THE LIMITS OF ALTRUISM

donation, as in the cases involving presumed consent, we shall leave those questions for a separate inquiry.

"The question before the court in *Curran* was whether a non-custodial parent, Mr. Tamas Bosze, could compel the production of his three-year-old twins for blood testing and possible bone marrow transplant in order to save the life of their twelve-year-old half-brother, Jean Pierre, who would surely die without the transplant."<sup>50</sup> The mother and legal guardian of the twins, Nancy Curran, "refused to provide consent for the procedure, leaving the court to decide, not only a case of first impression, but one which would shape future jurisprudence on altruistic donations from minors."<sup>51</sup> Two decisions were issued: first a pronouncement from the court in September 1990 and later a written ruling. Neither opinion offered relief for young Pierre.<sup>52</sup>

Less than a week before Christmas, on December 20, 1990, Justices of the Illinois Supreme Court issued a written opinion announcing why they refused to grant Bosze's demand for an injunction. The Court framed its decision on privacy principles, arguing that compelling blood tests from the twins would burden their right to privacy.<sup>53</sup> Ironically, the twins had been required to submit to blood tests to establish paternity, which would not save anyone's life.<sup>54</sup> By the time the court issued the written opinion, Jean Pierre had already died.<sup>55</sup>

Altruism can have the multiplying effect described in the Green case, where an act of generosity is reproduced many times over. What we must appreciate, however, are the unique ways in which altruism can be manufactured, masked, and manipulated as a proxy for other values and emotions triggered by intimacy. *McFall* and *Curran* expose the limits of that framework. The cases can also be read as outliers on both ends—donors who refused to cave in, and patients unwilling to accept their relatives' refusal.

The question for Jake Linford, then, is why attempt to preserve altruistic meaning, if altruism is a corruptible value? Why promote altruism if that platform fails to generate an adequate supply of organs?

<sup>50.</sup> Id. at 1320-21; see also Michele Goodwin, My Sister's Keeper?: Law, Children, and Compelled Donation, 29 W. NEW ENG. L. REV. 357, 389 (2007).

<sup>51.</sup> Curran, 566 N.E.2d at 1321; see also Goodwin, supra note 50, at 389.

<sup>52.</sup> Curran, 566 N.E.2d at 1345.

<sup>53.</sup> Goodwin, supra note 50, at 389.

<sup>54.</sup> Curran, 566 N.E.2d at 1320.

<sup>55.</sup> Goodwin, supra note 50, at 390.

# C. Crowding Out

In a recent book chapter published by the American Enterprise Institute, Richard Epstein observes that "[t]here remains one last bastion of opposition to the use of financial incentives in kidney transplantation."<sup>56</sup> The bastion that Epstein refers to is a communitarian ethic that suggests altruisticallyminded folks will be so turned off by incentives of any kind that they will withhold their organs and refuse to donate.<sup>57</sup> Or, the altruist will be displaced by the demand for incentive oriented players.<sup>58</sup> The altruist, it is argued, will be crowded out.<sup>59</sup>

The threat of "crowding out" hovers like a foreboding cloud over transplant theory, heightening a sense of anxiety and fear among antiincentive proponents. Why risk a steady (albeit inadequate), reliable source of organs to experiment with incentive programs that may not work? If the altruistically-minded horde their organs in dissatisfaction with market based approaches, organ shortages may be further intensified. The trouble with the crowding out speculation in organ transplantation is that the theory is difficult to prove, but also a challenge to disprove. Nevertheless, there is no reason to believe that a significant fraction of the current donor pool would resist the emotional pull to donate an organ to a spouse or sibling.

The more relevant question is if crowding out occurs, would it shrink or expand the full supply of organs? In other words, what underlies fear about crowding out? Is it that organ supplies will shrink? Or, that there is real value in a diversified organ supply pool? If our concern is the former, then there may be less to be concerned about as it can be satisfied by an empirical response. If the fear is the latter, such objections might seem more difficult to overcome. The lesson of blood banks, sperm, and ova help to place crowding out in perspective.

Richard Titmuss warned against introducing incentives into the blood and organ supplies.<sup>60</sup> His admonitions against incentives were cloaked in concern for public health and safety. For example, Titmuss urged that incentives induce only the "Skid Row donor types" to participate in blood donation and that the poor would infect the blood supply.<sup>61</sup> On closer inspection, Titmuss was far less generous. Such claims included racial imagery and overtones of "Negroes" waiting in line to sell their blood who, one could assume, would pollute the blood supply simply based on their

<sup>56.</sup> Epstein, supra note 6, at 92.

<sup>57.</sup> Id. at 92-93.

<sup>58.</sup> Id. at 92.

<sup>59.</sup> Id.

<sup>60.</sup> RICHARD M. TITMUSS, THE GIFT RELATIONSHIP: FROM HUMAN BLOOD TO SOCIAL POLICY, 76-77 (1971).

<sup>61.</sup> Id. at 150-51.

race.<sup>62</sup> The substance of Titmuss' claims are largely refuted and disproved because blood testing—not skin color, income, or literacy—determine the quality of one's blood for purposes of donation.

Most importantly, a shift from a donor's altruism to his compensation does not taint the quality and health of his or her blood and organs. The lessons learned from Titmuss' oversimplification are treated in detail elsewhere.<sup>63</sup> For my purposes here, it is enough to note that Titmuss was wrong. Incentives for blood did not crowd out the altruistic. Indeed, a very generous public continuously responds to blood procurement campaigns. By the breadth of these campaigns at high schools, churches, offices, and universities, it would seem that the altruistically-minded are unfazed by others choosing to accept payments for blood donations.

Ultimately, crowding out claims remain a point for empirical inquiry. Crowding out claims must be scientifically answered by pilot programs. Without empirical evidence, we are left to unreliable speculation that organ shortages will be exacerbated by the introduction of incentive based programs, including those of the type offered by Linford.

## D. Preserving Altruism or Promoting Other Values?

Linford identifies altruism as being chief among the standards that should reinforce incentive based programs, including his own. This Essay offers an alternative view of the standards most important in shaping incentive based programs. The relevant inquiry, I think, is what standards should attend pilot programs. Altruism may not be chief among them. Rather, dignity, trust, and autonomy are the more relevant values to be preserved and promoted in organ transplantation.

Autonomy, exercised through choice, will permit altruistic as well as incentive based donations. As discussed earlier, fraud, pressure, and coercion can influence (and undermine) altruistic organ donations and the effects can be as, if not more, pernicious than incentive based donations. It is precisely because altruistically based organ donations are less prone to suspicion of coercion, fraud, pressure, and manipulation that they are more likely to fly under the radar of protection for donors. As a consequence, preserving altruism may not lead to greater satisfaction for donors and recipients, but rather, reify the notion that such donations are exercised without a cost. The costs may be exactly that which the altruist may wish to ward off, including greed, coercion, and a loss of dignity.

Altruistic meaning is sacrificed even in altruistic based programs, including the current U.S. model, and that meaning cannot be restored in a

<sup>62.</sup> Id. at 152.

<sup>63.</sup> Goodwin, The Body Market, supra note 9, at 604-06.

system where children and the mentally incompetent are called upon to rescue siblings and other relatives.<sup>64</sup> Indeed, with the aid of advanced medical technologies—and under the guise of altruism—some parents have created savior siblings—children birthed specifically for the purpose of saving others.<sup>65</sup> This does not make altruism irrelevant to organ transplantation, but it might suggest that as an independent variable, its significance is slightly misplaced and overstated.

Independent of incentives, we can predict that altruistic meaning will morph in coming years as the shortfall in organs leads to severe rationing and secondary altruism markets such as the use of children and the mentally incompetent.

# PART III: SCHOLARSHIP BASED PROGRAMS

Most incentive based proposals for organ donation propose the use of direct financial incentives. Missing from this discourse is a focus on other incentive tipping points that might influence or trigger organ exchanges. Linford's intuition that more than cash will matter in incentive based programs deserves consideration. Indeed, charitable donations in the name of organ donors, scholarships, medical insurance, loan forgiveness, and mortgage forgiveness should be among the types of programs considered. To be sure, non-cash based incentive programs do not preserve altruism, but neither do they detract from altruistic principles although they vary by scale. Rather, non-cash based incentives might be more palatable than direct cash because the financial consideration is less evident and perception matters in organ exchanges.

Linford's proposal attempts to tap into the tipping point. It provides the safeguards found in the current transplant system, while offering liberation (of sort) from the current altruistic program. The Linford Plan would provide

<sup>64.</sup> See Strunk v. Strunk, 445 S.W.2d 145, 145-46 (Ky. 1969) (discussing whether a court has the ability to permit a kidney to be removed from an incompetent person for the purpose of being transplanted into the body of his brother). Three unreported Massachusetts decisions addressed whether parental authority to consent to similar medical procedures involving twins was permissible. As unreported cases these decisions were not readily accessible to judges and law clerks in other jurisdictions. *Foster v. Harrison*, No. 68674 (Cutter, Single Justice, Eq. Supr. Jud. Ct. (Mass.) Nov. 20, 1957); *Huskey v. Harrison*, No. 68666 (Whittemore, Single Justice, Eq. Supr. Jud. Ct. (Mass.) Aug. 30, 1957); *Masden v. Harrison*, No. 68651 (Counihan, Single Justice, Eq. Supr. Jud. Ct. (Mass.) June 12, 1957). See also Little v. Little, 576 S.W.2d 493, 494, 500 (Tex. Ct. App. 1979) (opining that the mother had the legal authority to substitute judgment for her fourteen-year-old mentally incompetent daughter for purposes of consenting to a kidney donation); Hart v. Brown, 289 A.2d 386, 386, 391 (Conn. Super. Ct. 1972) (holding that parents have the authority to require their seven-year-old daughter to surrender her organ for donation to her twin sibling).

<sup>65.</sup> GOODWIN, BLACK MARKETS, supra note 10, at 77.

tuition, fees, and living expenses at a four-year university or a job training program to which the donor-scholar qualifies for admission.<sup>66</sup> Unlike current altruistic based programs, participants in the Linford proposal would have to be at least eighteen years or older.<sup>67</sup>

Linford understands the need for more living donors entering the system. He rightly acknowledges that living donations are optimal. Living donors are ideal organ providers for kidney patients—their organs are far more viable than those coming from cadavers. More importantly, for the organ contributor, the risks of living donation are minimal; three deaths in one thousand, with two deaths in a thousand attributable to anesthesia. Once we are past the question of personal costs and whether they are too high to promote a living donation system, then we must take up the question of what proposal systems are best suited to encourage organ exchanges?

With Linford's proposal, we are left to ask whether there are any particular problems with tying organ incentives to education. The answer is not really. Scholarships are utilized frequently to promote positive social agendas. Normally such programs are to transform the individual receiving the scholarship, with a promise that society will somehow receive a benefit by a better educated populace. Linford's program provides a direct social benefit, whose affect is immediate, and not a promise.

Critics of Linford's proposal might suggest that a scholarship program will reach only those classes of individuals best positioned to attend college. Increasingly, that population is poor middle class, meaning that their values are from the middle, but the resources that follow can no longer provide for college, home ownership, and debt-free living. Thus, the critique might be that on balance more middle class and fewer low income individuals would benefit from the program. Some scholars might find excluding the most poor an acceptable consequence of incentive programs as they believe that those most impoverished are far more vulnerable to exploitation and coercion.

A second criticism against the Linford Plan is that it would reach only a fraction of the population—those choosing to attend college. That population is only a fraction of the larger American populace. A more robust plan, they might argue, would extend beyond those willing and interested in attending college. Linford answers this by allowing for an incentive for those willing to participate in job training programs.<sup>68</sup> This solution shows the breadth of his program, but value issues are exposed. For example, should the program be limited to attendance at state universities? Not all state universities are equal in resources and quality,

<sup>66.</sup> Linford, supra note 21, at 267, 270-71.

<sup>67.</sup> Id. at 271.

<sup>68.</sup> Linford, supra note 21, at 267 & n.8.

and thus the value of the degree and payment may differ. Would it be better to set a fixed scholarship payment to equalize the scholarship incentive? The scholarship payment disparities are further highlighted between public, private, and Ivy League universities.<sup>69</sup>

Further, a college education may offer a different value to students attending the same university. A college scholarship for an economically disenfranchised student may offer a heightened value than for the student from a wealthier family even at the same university. A scholarship that affords a student a degree in engineering may have a more significant payout over the lifetime of the scholarship recipient than a degree in the humanities. But personal value will also matter and that is difficult to measure.

It will always be difficult to quantify the value of what a college education means as its value is elastic, determined in part by what it means to the recipient. That does not mean that an inquiry to adjust the value of scholarships for organs is futile. Rather, it suggests that some issues remain important for future considerations. Among the other issues associated with scholarships will be who pays—the state, federal government, private charities, or individuals?

Finally, determining whether the scholarship can be transferred or if the donor can serve as proxy for another should be answered. Parents or other family members may wish to step in and offer a kidney to help a relative attend college. Such a plan would not seem unreasonable as college tuition for many students is underwritten by their parents. Equally, parent-donors may wish to transfer the scholarship from one child to another based on who the parent perceives to be most worthy of the scholarship—or who will use it best. Equally, it could be foreseeable that a parent may want to set four children up with one year each of tuition-free college attendance. Should Linford's plan make allowances for such uses?

# PART IV: CONCLUSION

Jake Linford offers a sensible proposal for one of the most pressing medical and social issues of our times. His scholarship proposal offers a different vision from cash based incentive programs, which are unattractive

<sup>69.</sup> See Nat'l Ctr. for Educ. Stat., U.S. Dep't of Educ., Digest of Education Statistics 2006, Fast Facts, available at http://nces.ed.gov/fastfacts/display.asp?id=76 (last visited Apr. 19, 2009) (noting that the average cost of a college education at four-year public institutions for the 2005-2006 school year was \$12,108, while the average cost at four-year private institutions was \$27,317). These costs included tuition, fees, and room and board, similar to Linford's plan. See also *lvy League Institutions Surpass* \$40,000 Mark in Yearly Costs, THE REC. (Bergen County, N.J.), June 30, 2005, at A22 (noting that for the 2005-2006 school year, costs at each of the eight lvy League institutions topped \$40,000).

2009]

CONFRONTING THE LIMITS OF ALTRUISM

to some in the organ transplant community. The social benefits are immediate and apparent on multiple fronts.

Linford's goal is to preserve altruistic meaning while increasing organ supply. One can easily glean from his project a sophisticated understanding of the tensions captured in organ procurement debates. Chief among the issues hotly debated are the potential for coercion and exploitation of the poor and minority in an incentive based approach. Linford attempts to reach a tipping point in this project. By that, his project is situated to be inviting to middle as well as low income participants, and yet not so transparently cash based that it would cause a crowding out effect among purist in the altruism community.

The challenge for Linford and others with similar proposals lies not in preserving altruism as its very meaning is conflated with other values that independently may be more socially compelling than altruism on its own. Those values include dignity, autonomy, and trust in the organ transplantation system (and those who work in the system). Rather, it seems, the challenge is crafting legislation that will inspire legislative action. Linford is certainly on the right track.