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STUMBLING TOWARD EQUITY: THE ROLE OF GOVERNMENT IN KIDNEY TRANSPLANTATION

Laura G. Dooley*
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In Mortal Peril, Professor Epstein is critical of the current, regulated system for organ donation and suggests that a market for organ tissue would better meet the needs of patients. In this response to Professor Epstein, Professor Laura Dooley and Dr. Robert Gaston pair their skills to attack Professor Epstein's analysis. As they have done on several other occasions, Professors Dooley and Gaston argue that the kidney donation and transplantation arena is fraught with racial inequity, and that Professor Epstein's proposal for a market in kidneys will exacerbate this inequity. The authors maintain that to prevent the poor from being excluded from transplants, the government plays a critical (if imperfect) role in the allocation of these scarce resources. Furthermore, government intervention is acceptable to correct past discrimination because there is scientific evidence that the disproportionate incidence of kidney failure in African Americans is related to the evolutionary pressures of slave trading and slavery. Professors Dooley and Gaston also defend their previous efforts to change the government system of allocation and characterize the government's willingness to adopt their recommendations as an appropriate response to scientific research rather than a governmental susceptibility to lobbying from special interest groups. Finally, the authors criticize Professor Epstein's argument that dialysis is a viable alternative to transplantation because there are significant differences in "quality of life, morbidity and survival." Professors Dooley and Gaston conclude that government intervention is necessary for maintaining the equity in kidney transplantation that a market system would not.

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I. INTRODUCTION

In *Mortal Peril*,¹ a comprehensive work examining health care in the United States, Professor Richard A. Epstein elegantly assails the concept that health care should be viewed as a positive right. For the government to grant such a positive right, it must back its promise with resources sufficient to address perceived needs. Unfortunately, available resources are finite, and health care is but one competitor among many for their use. In the context of kidney transplantation, which in many ways is a microcosm of the larger health-care rationing problem, Congress first acted in 1972 to grant patients with irreversible kidney failure the right to government-subsidized, long-term care in the form of either dialysis or transplantation.² As Professor Epstein perceptively recognizes, the creation of this positive right eventually engendered creation of a quasi governmental agency, the United Network for Organ Sharing (UNOS), charged with overseeing transplantation in the United States.³ Among other responsibilities, UNOS developed a point system to deal with the difficult problem of how to allocate the scarce kidneys available from cadaveric donors among the large group of hopeful transplant recipients.⁴

In a prior series of writings coauthored with Professor Ian Ayres,⁵ we proposed modifications to that point system that would, we hoped, lead to a more equitable distribution of kidneys. For largely historical reasons,⁶ the point system relied on HLA matching as the primary determinant of allocation.⁷ In our view, the empirical medical data

1. RICHARD A. EPSTEIN, *MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE?* (1997).

2. See Social Security Amendments of 1972, Pub. L. No. 92-603, § 299I, 86 Stat. 1329, 1463-64.

3. See EPSTEIN, *supra* note 1, at 263. The statutory framework authorized the creation of an Organ Procurement and Transplantation Network (OPTN) that was charged with creating a national waiting list for organs, a system to match available organs with individuals on the list, and criteria for allocating organs. See 42 U.S.C. § 274 (1994). A preexisting entity, the United Network for Organ Sharing (UNOS), was awarded the government contract to function as the statutory OPTN, and has retained that authority ever since.

4. The UNOS system awarded a sliding number of points according to the degree of mismatch of HLA antigens (HLA antigens are proteins on the surface of tissues that enable the immune system to distinguish foreign tissues). In addition, the system incorporated minimal credit for time spent on the waiting list, and awarded extra points to children (according to age) and those patients considered "presensitized"—that is, those who for medical reasons are difficult to match and are likely to reject a large percentage of donor kidneys. See *UNOS Policies 3.5* (last visited Mar. 10, 1998) <http://www.unos.org/About/policy_policies3_5.htm>.

5. See generally Ian Ayres et al., *Unequal Racial Access to Kidney Transplantation*, 46 VAND. L. REV. 805 (1993); Robert S. Gaston et al., *HLA Matching in Renal Transplantation*, 332 NEW ENG. J. MED. 752 (1995) [hereinafter Gaston et al., *HLA Matching*]; Robert S. Gaston et al., *Racial Equity in Renal Transplantation: The Disparate Impact of HLA-Based Allocation*, 270 JAMA 1352 (1993) [hereinafter Gaston et al., *Racial Equity*].

6. See Ayres et al., *supra* note 5, at 815-17.

7. Under the system then in place, up to 10 points were awarded according to degree of HLA matching; by contrast, patients were awarded only one-half of a point for each year spent on the waiting list. See Ayres et al., *supra* note 5, at 818-19 (describing particulars of UNOS point system then in existence).

did not support such heavy emphasis on matching, given new and constantly developing immunosuppressant technologies. The point system tended to disadvantage African American kidney patients, who received fewer kidneys with nearly twice the wait for a transplant as their white counterparts.⁸ Proposals circulating widely at that time would have imposed even greater emphasis on HLA matching, with potential for even more adverse impact on black end-stage renal disease (ESRD) patients. Given these developments, we proposed that the allocation scheme be modified in such a way that any disadvantage, current or potential, for African American patients be eliminated.⁹

Thus, as advocates for a subgroup of potentially disenfranchised beneficiaries of the quasi governmental program, we became, to Professor Epstein, emblematic of the sort of misguided, pernicious political pressures to which government monopolists become subject.¹⁰ That was never our purpose. Professor Epstein sees the ready response of UNOS to our concerns as a sign of the inability of government monopolists to withstand political pressures; we see it as an admittedly imperfect system responding to the veracity of our arguments as supported by scientific data. Although we are gratified that our efforts have provoked discussion in an audience more extensive than the transplantation community, our work cannot be divorced from the context in which it originated.

In short, the underrepresentation of blacks in transplantation statistics, a phenomenon that became inescapably obvious in the late 1980s,¹¹ could no longer be brushed aside as a problem only solvable by increasing black organ donation. The demographic reality dictated that increased black donation could meet only a small fraction of the need, due to the staggering incidence of kidney disease among African Americans.¹² Moreover, the HLA-based allocation system employed

8. At the time of our original article, statistics showed that black patients waited almost twice as long as whites for their first transplants (13.9 versus 7.6 months). See Ayres et al., *supra* note 5, at 808 (citing OFFICE OF INSPECTOR GEN., THE DISTRIBUTION OF ORGANS FOR TRANSPLANTATION: EXPECTATIONS AND PRACTICES 8 (1991)). The statistics, unfortunately, have not shown significant improvement in the intervening years. See *infra* notes 74 and accompanying text.

9. In particular, we proposed that those patients on the waiting list who were hard to match (because of the relative rarity of their antigen groupings as against the donor pool) should be awarded extra points so that they would have quicker access to kidneys that were not well matched to anyone else in the recipient pool. See Ayres et al., *supra* note 5, at 845. At the very least, we felt that waiting time on the list of potential recipients should be weighted more heavily in the point system than was true at the time. See *id.* at 846. UNOS responded on the latter point in amendments made to the point system in 1995 that increased points received for waiting list time. See UNOS POLICIES 3.5.6.1-3.5.6.2 (1995).

10. See EPSTEIN, *supra* note 1, at 279-80.

11. See Paul W. Eggers, *Effect of Transplantation on the Medicare End-Stage Renal Disease Program*, 318 NEW ENG. J. MED. 223 (1988). See generally Philip J. Held et al., *Access to Kidney Transplantation: Has the United States Eliminated Income and Racial Differences?*, 148 ARCHIVES INTERNAL MED. 2594 (1988).

12. See Ayres et al., *supra* note 5, at 810-11.

by UNOS was based on equivocal scientific evidence, with relative disregard of its impact on black Americans.¹³ The articles were successful in achieving our modest goals: national sharing¹⁴ of all kidneys based on matching is no longer a viable issue,¹⁵ and partisans in the debate can no longer cavalierly advance the notion that the African American community must donate its way into equity.

Our original argument was based on the premise that every patient who enters the queue for a kidney transplant should have roughly the same chance of receiving one. In this paper, we reaffirm that position. To the extent that government regulation is the exclusive means, at present, to realize that equitable goal, we believe it to be necessary. In part II, we discuss the history and current need for government involvement in transplantation. We will then turn our attention to the particulars of kidney transplantation, and why allocation has been such a difficult problem. Part III will describe the special problems presented by the proportionally greater incidence of ESRD in the African American population. We then take on the question whether underrepresentation of black patients is a legitimate concern for policy makers. Part IV explains how a combination of demographic factors and UNOS policy resulted in the underrepresentation of black patients in kidney transplantation, long understood to be the preferred mode of treatment for ESRD. Finally, in part V we discuss the outlook for the future in kidney transplantation and offer observations about the need for a clear equitable goal in the face of fluid medical evolution.

Professor Epstein's book examines the philosophical underpinnings of the entire health-care system, questioning the wisdom of any government involvement in it. Lacking the breadth of resources that enabled Professor Epstein to simultaneously address all the ills plaguing health care in this country, we limit our focus to the relatively confined world of kidney transplantation. This world, though, is one where patients live and die, where policy becomes reality daily for every patient awaiting a suitable kidney, tethered in the meantime by

13. *See id.* at 825-36.

14. Professor Epstein erroneously asserts that "today all matches are done on a national basis." EPSTEIN, *supra* note 1, at 266. Only the best-matched kidneys (that is, those with a zero-antigen mismatch) are shared nationally; others are distributed according to the UNOS point system by OPOs (Organ Procurement Organizations) within regions, unless the OPO has been granted a variance by UNOS. *See Policy: Organ Distribution* (visited Oct. 14, 1998) <http://www.unos.org/About/policy_policies3_5.htm>.

15. In the early 1990s, flush with perceived success in implementing national organ sharing of six-antigen-matched kidneys, some vocal members of the transplant community began a strong push for mandatory national cadaveric kidney allocation based solely on HLA matching, arguing that every kidney procured within the United States should go to the candidate with the closest HLA match. *See generally* William E. Braun, *Every Kidney Counts*, 327 *NEW ENG. J. MED.* 883 (1992); David W. Gjertson et al., *National Allocation of Cadaveric Kidneys by HLA Matching: Projected Effect on Outcome and Costs*, 324 *NEW ENG. J. MED.* 1032 (1991); Steve Takemoto et al., *Survival of Nationally Shared, HLA-Matched Kidney Transplants from Cadaveric Donors*, 327 *NEW ENG. J. MED.* 834 (1992).

needles and hoses to lifesaving but vigor-sapping dialysis machines. On matters of common law and positive rights, we defer to Professor Epstein's expertise. But until the powers that be decide that access to life-renewing therapy is no longer a public concern, we will continue to agitate for equity in the system.

II. DOES THE GOVERNMENT HAVE A LEGITIMATE ROLE TO PLAY IN RENAL TRANSPLANTATION?

The persistent problem of a shortage of transplantable organs has prompted a myriad of responses from scholars in many different fields. Most notably, the literature is replete with arguments for and against the idea of a free market in transplantable organs.¹⁶ Rather than revisit that debate, we will focus here, as before, on how allocative decisions should be made once the available resources have been gathered, and on whom that decision-making responsibility should principally fall.¹⁷

Indeed, even some commentators who have endorsed a market approach to organ transplantation on the supply side have expressed concern about markets on the demand side. For example, James Blumstein has noted the "special claim that while wealth inequality is acceptable as a general matter, it is unacceptable as a basis for deciding which persons are to be recipients of organ transplants."¹⁸ He further notes that this, a primary objection of those who would continue the government policy forbidding any commercial trade in organ transplants, could be assuaged by limiting market-reform efforts to the supply side, and by instituting "public subsidy for those whose inadequate level of wealth bars access."¹⁹

It seems clear to us that absent radical changes in the ESRD patient population, the troubling ethical spectacle of the poor forgoing

16. See, e.g., Lloyd R. Cohen, *Increasing the Supply of Transplant Organs: The Virtues of a Futures Market*, 58 GEO. WASH. L. REV. 1 (1989); Gregory S. Crespi, *Overcoming the Legal Obstacles to the Creation of a Futures Market in Bodily Organs*, 55 OHIO ST. L.J. 1 (1994); Richard Schwindt & Aidan R. Vining, *Proposal for a Future Delivery Market for Transplant Organs*, 11 J. HEALTH POL. POL'Y & L. 483 (1986).

17. We note that Professor Epstein was himself unwilling to support a futures market on the supply side. See EPSTEIN, *supra* note 1, at 253. We, like Professor Epstein, are willing to consider the benefits of commerce in living donor transplants. See *id.* at 253-61. If difficult issues of consent and coercion were to be resolved, then the increase in supply might help remedy the distributive problem that instigated our work in the first place—a concededly salutary effect. However, under current law such exchanges are illegal, and such an approach to the organ shortage is clearly outside current norms in the transplantation community. See *infra* note 31 and accompanying text and text accompanying notes 99-104.

18. James F. Blumstein, *The Use of Financial Incentives in Medical Care: The Case of Commerce in Transplantable Organs*, in JUSTICE AND HEALTH CARE: COMPARATIVE PERSPECTIVES 9, 31 (Andrew Grubb & Maxwell J. Mehlman eds., 1995).

19. *Id.* Professor Blumstein further notes, though, that those who would support the public funding of organ purchases would be somewhat hard-pressed to make out a justification for this particular form of government largesse in the face of other medical needs that go unmet. See *id.* at 31-32.

kidney transplantation while the rich enjoy access necessitates some kind of ongoing government involvement, at least on the allocation side. As Guido Calabresi and Philip Bobbitt noted in their book *Tragic Choices*, a market superimposed on an existing unequal distribution of wealth "presents the wrenching spectacle of a rich man and a poor man bidding against each other for life."²⁰ Those directly involved in the organ transplant community have similarly rejected the market as an acceptable medium of allocation.²¹

Our argument that government must remain involved in the allocation system for cadaveric kidneys, of course, begs the logically prior question of why the government should be in the business of providing health-care benefits to those citizens who cannot otherwise afford them. This vexing question has been, and continues to be, a subject of hot debate. Einer Elhauge argues convincingly that our collective

moral sense that health care should be distributed without regard to ability to pay is, at root, the same moral sense we have that other needs should also be met . . . but far less diluted by concerns about administrative problems and undermined productive incentives Health care commands a greater commitment to equality because it is here that the reason for resisting equality vanishes, making any denial seem far more hard-hearted.²²

For our purposes here, we note our approval of the federal government's long-standing commitment to the treatment of ESRD for all its sufferers, rich and poor, and leave the larger debate to the philosophers. We do note, however, that the privileged status of organ-transplant programs in government funding might well derive from a commonly shared sense that organs are a kind of "community re-

20. GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* 33 (1978). The authors further explain the costs of a market approach:

In effect, a market at the second order [allocation], because it requires that a price be used, brutally emphasizes the first-order decision's implicit rejection of the pricelessness of the good being allocated At least as important as a limitation of the market is its dependence on the existing distribution of wealth. This dependence is accentuated when the market is used to make only the second-order determinations; once the first-order determinations are made collectively, it is implausible to say that by using the market we have merely given a resource to those who are willing to give up what it takes to produce it. Instead we are openly testing relative desire and this test is necessarily warped if the measure of desire—a single dollar, for example—has a different importance for different choosers.

Id. at 32-33.

21. See, e.g., *Report of the Massachusetts Task Force on Organ Transplantation*, in *HUMAN ORGAN TRANSPLANTATION* 211 (1987).

Rationing by financial ability says that we do not believe in equality and that we do believe that a price can and should be placed on human life and that it should be paid by the individual whose life is at stake. Neither belief is tolerable in a society in which income is inequitably distributed.

Id. at 233, quoted in Lloyd R. Cohen & Melisa Michelsen, *The Efficiency/Equity Puzzle and the Race Issue in Kidney Allocation: A Reply to Ayres, et al. and UNOS*, 1996 ANN. REV. L. & ETHICS 137, 182 n.132.

22. Einer Elhauge, *Allocating Health Care Morally*, 82 CAL. L. REV. 1449, 1490-91 (1994).

source to be used for the good of the community as the community decides."²³

In the United States, the federal government first became actively involved in the treatment of ESRD when Congress passed a 1972 amendment to the Social Security Act that authorized payment of eighty percent of the cost of treating ESRD (either through dialysis or transplantation).²⁴ The government's focus on this particular health issue seems to have stemmed from its long-standing commitment to provide care for military veterans through the network of government-run Veterans' Administration hospitals.²⁵ At the same time, agencies within the Public Health Service were exploring the advancing technologies for treating kidney disease through both dialysis and transplantation.²⁶ These programs prompted the government to undertake a policy review of the available kidney treatment protocols; a committee of experts formed in the mid-1960s produced a report recommending that the federal government use the Social Security system to establish a national treatment benefit program for ESRD.²⁷ During the ninety-second Congress when the ESRD program was among many being considered, apart from the famous incident in which a patient was dialyzed live in the hearing room for members of the House Ways and Means Committee, there was surprisingly little debate on the proposed program.²⁸ But Congress unmistakably and deliberately sought to obviate the tragic choice that faced American ESRD patients who could not afford access to the emerging lifesaving technologies. As the sponsoring senator put it on the Senate floor: "How do we explain that the difference between life and death is a matter of dollars? How do we explain that those who are wealthy

23. Peter H. Schuck, *Government Funding for Organ Transplants*, 14 J. HEALTH POL. POL'Y & L. 169, 180 (1989) (quoting John A. Robertson, *Supply and Distribution of Hearts for Transplantation: Legal, Ethical and Policy Issues*, 75 CIRCULATION 77, 86 (1987)). Schuck notes that the notion of a "moral community" that demands that all members "begin with an equal moral claim to the organ, just as they have an equal obligation to support (presumably through taxes) the like claims of others[.]" seems to undergird the findings of the task force appointed by Congress in 1984 to evaluate the federal organ transplant programs. *Id.*; see also U.S. DEP'T OF HEALTH & HUMAN SERVS., TASK FORCE ON ORGAN TRANSPLANTATION, ORGAN TRANSPLANTATION: ISSUES AND RECOMMENDATIONS (1986).

24. See Social Security Amendments of 1972, Pub. L. No. 92-603, § 299I, 86 Stat. 1329, 1463-64.

25. See RICHARD A. RETTIG & ELLEN L. MARKS, U.S. DEP'T OF HEALTH & HUMAN SERVS., IMPLEMENTING THE END-STAGE RENAL DISEASE PROGRAM OF MEDICARE 25 (Health Care Financing Grants and Contracts Report, 1981). By the time of the 1972 Medicare amendments, the Veterans' Administration had established 44 dialysis treatment centers and a home dialysis program. See *id.*

26. See *id.* at 26.

27. See *id.* at 26-27 (citing U.S. BUREAU OF THE BUDGET, REPORT OF THE COMMITTEE ON CHRONIC KIDNEY DISEASE (1967)).

28. See *id.* at 29. In fact, the ESRD amendment was never formally considered through committee processes; it was introduced on the Senate floor and quickly adopted, approved by a joint conference committee and both houses, and incorporated into the bill President Nixon signed. See *id.*

have a greater chance to enjoy a longer life than those who are not?"²⁹ The program was approved by Congress with very little opposition.³⁰

In 1984, Congress passed the National Organ Transplant Act (NOTA),³¹ legislation that had the effect of taking the federal government's role in kidney transplantation beyond funding to issues of allocation. NOTA required the Department of Health and Human Services (HHS) to establish a Task Force on Organ Transplantation, which in turn was to be charged with preparing a report on all aspects of organ transplantation in the United States.³² NOTA further authorized the establishment of an organ procurement and transplantation network (OPTN), which among other things was to develop criteria for the allocation of organs.³³ The OPTN contract was awarded in 1986 to a preexisting organization, the United Network for Organ Sharing (UNOS), which has maintained the government contract since. The statutory language itself reflects Congress's perennial concern: it requires that organs be allocated "equitably among transplant patients according to established medical criteria."³⁴

We set up our first article to illustrate the tension between these norms of efficiency and equity which Congress had mandated be used to allocate cadaveric kidneys for transplantation.³⁵ Epstein, in turn, equates the two—for him, apparently, the only equitable allocation process is one that privileges efficiency.³⁶ But both terms are, of course, malleable. We never intended to sacrifice kidneys at the altar of political correctness in racial matters; to the contrary, our proposals always attempted to account for documentably superior outcomes even when that would tend to benefit white recipients.³⁷ Rather, we believed then, and still do, that when scientific data are in sharp dispute as to the relative medical prospects of different potential recipients, all those patients should have a roughly equal chance at receiving a kidney, regardless of race. The problem was that the point system used by the government monopolist did not achieve that level

29. 118 CONG. REC. 33,003 (1972) (comments of Sen. Vance Hartke (D-Ind.)), *quoted in* RETTIG & MARKS, *supra* note 25, at 30. *See generally* Richard A. Rettig, *The Policy Debate on Patient Care Financing for Victims of End-Stage Renal Disease*, LAW & CONTEMP. PROBS., Autumn 1976, at 196.

30. *See* Rettig, *supra* note 29, at 196, 224-25.

31. National Organ Transplant Act, Pub. L. No. 98-507, 98 Stat. 2339 (1984) (codified at 42 U.S.C. §§ 273, 274(a)-(c) (1988 & Supp. II 1990)), *amended by* Health Omnibus Programs Extension of 1988, Pub. L. No. 100-607, 102 Stat. 3049 *and* Transplant Amendment Acts of 1990, Pub. L. No. 101-616, 104 Stat. 3279.

32. *See generally* U.S. DEP'T OF HEALTH & HUMAN SERVS., *supra* note 23. The report ultimately produced by the Task Force echoes the view that donated organs are a scarce national resource and thus that the allocation system must be equitable. *See generally id.*

33. *See* 42 U.S.C. § 274(b) (1994).

34. *Id.* § 273(b)(3)(E).

35. *See* Ayres et al., *supra* note 5, at 837-41.

36. *See* EPSTEIN, *supra* note 1, at 275-78.

37. For example, our proposals retained the nearly absolute preference given six-antigen matches. *See* Ayres et al., *supra* note 5, at 845-46.

of equity because it used an allocation device (partial matching) that lacked, in our view, adequate scientific support to justify the disparate racial effect it had.

Ironically, it was precisely because a system based on matching gave a scientific patina to kidney allocation that led many of our critics to assume that our proposal would sacrifice efficient outcomes for our "politically correct" equitable goal.³⁸ Thus, Professor Epstein devotes a fair amount of attention to an argument that one of our proposals (that rare-antigen points—which will often, but not exclusively, be awarded to African American patients—be used in the point system to make up for the relative lack of access suffered by patients who are unlikely ever to receive one of the six-antigen match kidneys) is an example of a neutral rule proffered in the service of an overt political goal.³⁹ The truth is that the status quo we criticized, namely the UNOS point system for distribution of cadaveric kidneys, produced unequal access to transplantation for patients of different races, thereby sacrificing equity *for no good efficiency reason*. Our argument was simple: matching should not be the primary determinant of who gets a kidney when the medical data do not show that matching produces superior outcomes. Thus, we tried to calibrate our proposal as carefully as possible to the emerging medical evidence: we retained the preference for matching when the data supported its efficacy (as to the very well-matched kidneys) but argued for other factors to have more weight when matching showed equivocal effect on outcome.⁴⁰ We further suggested that "rare antigen" points might be awarded to those patients whose combination of antigens would give them less than a ten percent chance of qualifying for a matching preference,⁴¹

38. See EPSTEIN, *supra* note 1, at 275-77. See generally Cohen & Michelsen, *supra* note 21.

39. See EPSTEIN, *supra* note 1, at 277-78. Professor Epstein's illustration of an unacceptable "neutral rule" is itself quite telling. He asks us to imagine a teacher who institutes a "neutral" grading system that counts spelling errors for the reason that whites will thereby be benefitted. His point is that we would not, and should not, tolerate such a rule that would obviously mask racism. He then argues that to flip the rule—ignore spelling errors—suffers from the same defect and is equally deplorable. See EPSTEIN, *supra* note 1, at 277-78. First, his chosen hypothetical, perhaps not accidentally, paints the minority group as inevitably inferior. Second, the argument does not sufficiently account for the fact that neutral rules often are employed for the benefit of the powerful group, but without the smoking gun of a record that says so explicitly. It has long been the goal of antidiscrimination law to try to unmask such motivations even when expressed in so-called neutral rules.

When Professor Epstein argues that the "right question to ask is which rule would you adopt if your population were all white or all black," *id.* at 278, we completely agree. And to properly respond to that question, policy makers must be mindful of emerging medical data and the ill, if unintended, effects of their policies. Indeed, it was in that spirit, in the kidney transplant context, that our earlier work sought to point out, and to the extent medically efficacious, remedy, the racial inequality produced by the "neutral" point system UNOS was using at the time.

40. See Ayres et al., *supra* note 5, at 845 (proposed modified point system).

41. See *id.*

and supported that suggestion by appealing to other circumstances in which the system accommodated patients with "medical bad luck."⁴²

Professor Epstein argues that we wrongly equated our proposal with prior concessions given to patients with O-type blood.⁴³ The "O rule," he asserts, is not a concession to the equitable claims of O patients; it is a rule that "make[s] sense on classical efficiency terms . . . [b]y making the more difficult match first, the allocation rule leaves the more suitable recipient in the pool and thus increases the probability that both matches will be successfully made."⁴⁴ Our proposal to include rare antigen points in the algorithm can be justified on the same efficiency rationale: a patient with rare antigens relative to the donor pool will be a more difficult match, and thus overall efficiency is heightened if that patient gets a preference as to a particular kidney that is not well-matched to anyone else on the recipient list, especially given the medical evidence that partial matching is a relatively poor predictor of successful outcome.

New evidence now seems to support our view that it is possible to achieve more equitable allocation (in terms of evening out the waiting times for all demographic groups) and get even more efficient outcomes (measured by graft and patient survival) than either the present system or other proposed ones.⁴⁵ A recent simulation-based policy study using data obtained both from UNOS and the United States Renal Data System demonstrated that an equity-based algorithm that assigned priority to African American recipients achieved the smallest difference in median waiting time while achieving the second-highest score for efficiency as measured by a quality-adjusted life expectancy.⁴⁶ This promising research suggests that it is possible to develop a carefully calibrated algorithm that optimizes medical benefit while achieving greater equity in waiting time.

Moreover, Professor Epstein is wrong when he asserts that the other causes (besides antigen-matching) for black underrepresentation in kidney transplantation—which he identifies as the proportionately higher number of black ESRD patients and the low level of

42. J. Michael Dennis, *A Review of Centralized Rule-Making in American Transplantation*, 6 *TRANSPLANTATION REV.* 130, 133 (1992) ("'Medical justice' is a principle based on compassion for patients with 'medical bad luck.' Because of their medical condition, these patients have a less-than-average chance to receive treatment. Medical justice dictates that they be given allocative preference.").

43. Kidneys harvested from donors with O-type blood, who are universal donors, could be transplanted into recipients who have any blood type. But because transplant candidates who have O-type blood can only receive O kidneys, UNOS developed a rule requiring that, except for a zero-antigen mismatch with a patient of another blood type, O kidneys must be allocated to O recipients. See Ayres et al., *supra* note 5, at 821-22.

44. EPSTEIN, *supra* note 1, at 279 (citing Cohen & Michelsen, *supra* note 21, at 163).

45. See generally S.A. Zenios et al., *Allocation of Kidneys to Patients on the Transplant Waiting List: Assessing the Trade-Off Between Equity and Efficiency*, 8 *AM. SOC'Y NEPHROLOGY* 708A, 708A (1997) (program presentation abstract).

46. See *id.*

black organ donation—are not “attributable to past abuses or to present discrimination.”⁴⁷ Studies show that the relatively lower level of black donation may well be the result of a breakdown in communication between largely white health-care providers and families of black patients whose conditions render their organs suitable for transplantation.⁴⁸ And as we explain in the next section, the high incidence of ESRD in the black population may be traceable to a combination of genetic and socioeconomic factors that cannot plausibly be divorced from the racism that infected our country and found its most obscene expression in the institution of slavery.

III. END-STAGE RENAL DISEASE IN AFRICAN AMERICANS

In 1993, available data indicated that African Americans were at significantly greater risk of developing ESRD than were Caucasians or other minority populations.⁴⁹ Current data indicate that there has been no substantial change—in fact, the numbers were even more staggering in 1997.⁵⁰ The incidence of ESRD in African Americans from 1993 to 1995 (758 per million) was over four times that of Caucasians (180 per million), and ESRD prevalence during the same period was almost five times greater (2968 per million versus 666 per million).⁵¹ Hypertension was the most commonly stated cause of renal failure among African Americans, although blacks with almost any diagnosis were at greater risk than Caucasians of proceeding to dialysis or transplantation.⁵² Despite comprising only twelve percent of the general population, blacks now comprise fully a third of those with ESRD.⁵³

Professor Epstein takes the position that race should have no relevance in the kidney transplantation context, and faults us for what he perceives as our effort to inject politics into this arena.⁵⁴ We disagree, however, that the disproportionately higher incidence of ESRD in the African American community is a historical accident. Indeed, Professor Epstein ignores or misapprehends arguments advanced in our first article to justify why policy makers should be concerned about racial

47. EPSTEIN, *supra* note 1, at 275.

48. See Clive O. Callender et al., *Attitudes Among Blacks Toward Donating Kidneys for Transplantation: A Pilot Project*, 74 J. NAT'L MED. ASS'N 807, 807-09 (1982) [hereinafter Callender et al., *Attitudes*]; Clive O. Callender et al., *Organ Donation and Blacks: A Critical Frontier*, 325 NEW ENG. J. MED. 442, 442-44 (1991).

49. See Robert E. Qualheim et al., *Changing Patterns of End Stage Renal Disease Due to Hypertension*, 18 AM. J. KIDNEY DISEASES 336, 336 (1991); Stephen G. Rostand, *US Minority Groups and End-Stage Renal Disease: A Disproportionate Share*, 19 AM. J. KIDNEY DISEASES 411, 411 (1992).

50. See U.S. Renal Data Sys., *Excerpts from United States Renal Data System 1997 Annual Data Report*, 30 AM. J. KIDNEY DISEASES S50 (Supp. 1, Aug. 1997).

51. See *id.*

52. See U.S. RENAL DATA SYS., 1996 ANNUAL DATA REPORT 28 figs.II-8 & II-9 (1996).

53. See *id.* at 27 fig.II-6.

54. See EPSTEIN, *supra* note 1, at 274-80.

inequity in renal transplantation.⁵⁵ First, we argued that to ignore concerns about blacks' impaired access to kidney transplantation might be characterized as selective indifference, especially in light of the system's accommodation of other patients with difficulty accessing kidneys.⁵⁶ Second, we argued that a response to blacks' disparate access is warranted given the past and present discrimination contributing to the heightened rate of ESRD among blacks.⁵⁷ In the years since that article appeared, scientific evidence supporting our second argument continues to mount.

The key element contributing to black ESRD seems to be high blood pressure. Most afflicted blacks have a form of high blood pressure known as low-renin hypertension. Evidence of a strong genetic link between low-renin hypertension and kidney failure in blacks is becoming well established, focusing on the role of dietary salt intake.⁵⁸ A current working hypothesis is that the kidneys in black Africans evolved under pressures of limited availability of salt and water, resulting in overexpression of cellular mechanisms favoring retention of those life-sustaining substances.⁵⁹ However, in the modern era, particularly in the American South, access to sodium and water is not restricted, and salt intake is quite high. Excess salt intake superimposed on a genetic predisposition to salt retention results in low-renin hypertension, which in turn may cause overt kidney injury. Some have suggested that passage to America in slave ships, with limited supplies of salt and water, might have exerted even more genetic pressure by favoring survival of those Africans best able to retain salt.⁶⁰

Along with the effects of high blood pressure and diet in African Americans is the causative impact of socioeconomic disadvantage, especially limited access to health care. It is well documented that many black ESRD patients never knew of nor received care for their high blood pressure prior to developing irreversible renal injury.⁶¹ In response to our 1993 article that appeared in the *Journal of the Ameri-*

55. See Ayres et al., *supra* note 5, at 841-43.

56. See *id.* at 841. The system gives preferences to patients with O-type blood and to those who are "presensitized" because of their relatively greater difficulty in matching most of the kidneys in the donor pool. See *supra* notes 4, 43-44 and accompanying text.

57. See Ayres et al., *supra* note 5, at 842-43.

58. See generally Suzanne Bergman et al., *Kidney Disease in the First-Degree Relatives of African-Americans with Hypertensive End-Stage Renal Disease*, 27 AM. J. KIDNEY DISEASES 341 (1996); James K. Bubien et al., *Liddle's Disease: Abnormal Regulation of Amiloride-Sensitive Na⁺ Channels by β -Subunit Mutation*, 270 AM. J. PHYSIOLOGY C208 (1996). See also Stephen G. Rostand et al., *Renal Insufficiency in Treated Essential Hypertension*, 320 NEW ENG. J. MED. 684 (1989) (documenting link between hypertension and renal failure in African Americans).

59. See Kathy A. Fackelmann, *The African Gene?: Searching Through History for the Roots of Black Hypertension*, 140 SCI. NEWS 254, 254 (1991) (describing research by Clarence E. Grim suggesting that Africans with a salt-conserving gene or genes were more likely to survive the arduous journey into slavery).

60. See *id.*

61. See Qualheim et al., *supra* note 49, at 341.

can Medical Association,⁶² a writer in the *Economist* noted that “perhaps the most important question is: what can be done to lower black Americans’ high rates of catastrophic kidney disease?”⁶³ A National Institute of Health study is currently underway, with the goal of defining the true nature of renal disease in black Americans along with optimal strategies for intervention in this population.⁶⁴ Hopes are high that these efforts will indeed improve the situation. Nonetheless, for the immediate and foreseeable future, ESRD in America is likely to remain a disproportionately black problem.

IV. BLACK UNDERREPRESENTATION IN KIDNEY TRANSPLANTATION: A LEGITIMATE CONCERN?

Despite the overrepresentation of blacks among those with ESRD, black patients remain less likely to receive a transplant than Caucasians or other minorities. In 1995, fewer than 15% of black ESRD patients had functioning allografts, versus 34% of whites with ESRD.⁶⁵ Moreover, recent statistics indicate that blacks, though comprising 35% of those on waiting lists, receive only 22% of cadaveric kidneys.⁶⁶ Mean waiting time between listing and transplantation is over twice as long for blacks relative to whites and other minorities.⁶⁷ These data indicate that blacks’ access to this preferred treatment is a persistent and pervasive problem.⁶⁸

There is no simple explanation for the underrepresentation of blacks in transplantation, though it is possible to get a clearer picture of the problem by assembling data from a variety of sources. To receive a transplant, a patient with ESRD must successfully negotiate a rather complex process. First, the patient must be referred to a transplant center (usually by a nephrologist who also provides dialysis care). The transplant center then evaluates a potential candidate’s overall physical, mental, and social resources to determine ability to handle the demands of transplantation. Once a patient is deemed suitable, the search for a donor can begin. Because most transplant centers consider live donor transplants to offer superior outcomes, this

62. Gaston et al., *Racial Equity*, *supra* note 5.

63. *Transplants: The Colour of Kidneys*, *ECONOMIST*, Oct. 2, 1993, at 94.

64. The study is known as AASK (African-American Study of Kidney Disease). See W. Dallas Hall et al., *Short-Term Effects of Blood Pressure Control and Antihypertensive Drug Regimen on Glomerular Filtration Rate: The African-American Study of Kidney Disease and Hypertension Pilot Study*, 29 *AM. J. KIDNEY DISEASES* 720, 721 (1997).

65. See U.S. Renal Data Sys., *supra* note 50, at 860.

66. See Ann M. Harper & John D. Rosendale, *The UNOS OPTN Waiting List and Donor Registry: 1988-1996*, in *CLINICAL TRANSPLANTS 1996*, 69, 71 (J. Michael Cecka & Paul I. Terasaki eds., 1997). See generally UNOS, UNOS UPDATE, Summer 1997, at 35.

67. See Harper & Rosendale, *supra* note 66, at 69.

68. Back in 1988, Paul Eggers of HCFA noted that improving “trends in transplantation have not yet had much effect on black beneficiaries.” Eggers, *supra* note 11, at 229. Given the persistently dismal statistics, his statement still rings true.

is the initial course explored.⁶⁹ If no live donor is identified, a transplant candidate is then placed on the UNOS waiting list for a cadaveric kidney. Evidence suggests that African American patients are disadvantaged at almost every step of the process.

UNOS data indicate that black patients are less likely than whites to be listed for transplant prior to onset of dialysis treatments, implying a discrepancy in initial access to the transplantation process.⁷⁰ Once referred, however, it appears that black and white ESRD patients are equally likely to be deemed acceptable candidates.⁷¹ Another limiting factor seems to be the relatively greater difficulty black patients encounter in finding a suitable live donor.⁷² This discrepancy reflects both a lack of identified potential donors among black families and increased medical contraindications among available live donors (largely due to hypertension and diabetes). The net result is that black patients are relatively more dependent on cadaveric kidneys for transplant.⁷³

Once placed on the cadaveric kidney waiting list, statistics continue to show a significantly longer wait for African American patients.⁷⁴ We have already noted our concern that an allocation system based on matching is a primary force behind the discrepancy. Other explanations have been offered: for example, some studies have shown a relatively higher degree of presensitization among black patients, making them significantly more likely to have a positive cross-

69. See Eugene J. Schneitzer et al., *Increased Living Donor Volunteer Rates with a Formal Recipient Family Education Program*, 29 AM. J. KIDNEY DISEASES 739, 739 (1997). See generally M.R. Tankersley et al., *The Living Donor Process in Kidney Transplantation: Influence of Race and Comorbidity*, 29 TRANSPLANTATION PROC. 3722 (1997).

70. See generally Bertram L. Kasiske et al., *Characteristics of Patients Placed on the Transplant Waiting List Before Requiring Dialysis*, 8 J. AM. SOC'Y NEPHROLOGY 688A (1997) (poster session abstract). This conclusion was supported by a survey of dialysis units in the southeastern United States, which documented that African American patients were less likely to be referred for transplantation than Caucasians. See J. Michael Soucie et al., *Race and Sex Differences in the Identification of Candidates for Renal Transplantation*, 19 AM. J. KIDNEY DISEASES 414, 417 (1992).

Some have argued that black patients receive fewer transplants because they themselves choose not to pursue that treatment. If this is the case, and there are few data to support the contention, it would seem to reflect the impact of socioeconomic factors such as poverty, education, and lack of familiarity with the health-care system. Cf. Callender et al., *Attitudes*, *supra* note 48, at 807-09 (finding that black donation is hindered significantly by fear and distrust of the medical establishment).

71. At the University of Alabama transplant center, for example, 69% of both black and white patients evaluated are accepted as transplant candidates. See Tankersley et al., *supra* note 69, at 3722 tbl.1.

72. See *id.* at 3722-23. Though live donors provide kidneys for 24% of all kidney transplants, approximately 80% of those involve white recipients; less than 16% went to blacks. See U.S. RENAL DATA SYS., *supra* note 52, at F.36 tbl.F27.

73. Indeed, in Alabama, 57% of those patients activated on the waiting list between 1994 and 1996 were black. Telephone Interview with Sharon L. Hudson, Director, Transplant Data Registry, University of Alabama at Birmingham (Nov. 7, 1997).

74. Mean waiting time to transplant for those listed in 1992 was 483 days for whites and 900 days for blacks. See UNOS, UNOS UPDATE, May/June 1996, at 43 tbl.2.

match with any given cadaveric kidney,⁷⁵ which then excludes them as possible recipients of that kidney. Others have argued that black patients are more likely to be unreachable for transplant at the crucial time when a cadaveric kidney becomes available.⁷⁶

Professor Epstein points to statistics that show that blacks are better able to tolerate dialysis as support for the position that their underrepresentation in transplant numbers is not a pressing concern.⁷⁷ Further, he notes that

there already is a major redistribution of wealth through both special kidney programs and general Medicare and Medicaid programs *from white to black*. . . . Blacks, as a group, receive more benefit from the kidney program than they contribute . . . [n]or should anyone within the framework of current programs, claim that whites should obtain better access to any dialysis program because, pro rata, they have contributed a greater fraction to its cost of operation.⁷⁸

Thus, the argument goes, because blacks as a group are already deriving more benefit from ESRD programs than they contribute, why the outcry over transplantation?

Contrary to Epstein's implicit equation of dialysis with transplant as treatment options, there are vast differences in life on dialysis and life with a transplant. Despite substantial improvement in the medical aspects of chronic dialysis,⁷⁹ transplantation still provides better outcomes in terms of quality of life, morbidity, and survival.⁸⁰ As Dr. Sheldon Tobe has noted:

Renal dialysis may be used for a short period to allow a return of renal function to a preceding level, or long-term before renal transplantation. However, many persons with end-stage renal disease will require long-term dialysis because renal transplantation is not possible due to lack of donor availability or the recipi-

75. See JOEL D. KALLICH ET AL., ACCESS TO CADAVERIC KIDNEY TRANSPLANTATION 48 (1993). This study documented that 36% of black patients tested had positive crossmatches (meaning they possessed antibodies that clearly would reject the donor kidney). See *id.* Another group of researchers found 19% of a similar group of black candidates to have positive crossmatches, although the rate rose to 55% in those who had previously received blood transfusions (which stimulate antibody formation). See Ronald H. Kerman et al., *Influence of Race on Crossmatch Outcome and Recipient Eligibility for Transplantation*, 53 TRANSPLANTATION 64, 65 (1992). Because transfusions have become increasingly rare in patients awaiting transplantation, the high rate in both these studies may not be predictive; in fact, the experience at Alabama shows that no more than about 10% or 15% of primary black candidates are likely to have positive crossmatches. Thus, while we concur that presensitization is an important factor, we do not believe it adequately explains the racial disparity in transplantation.

76. See Fred P. Sanfilippo et al., *Factors Affecting the Waiting Time of Cadaveric Kidney Transplant Candidates in the United States*, 267 JAMA 247, 250 (1992).

77. See EPSTEIN, *supra* note 1, at 272.

78. *Id.* at 275.

79. For example, biocompatible membranes and erythropoietin therapy of anemia have been developed. For a full review of advances in chronic dialysis, see generally Stephen Pastan & James Bailey, *Medical Progress: Dialysis Therapy*, 338 NEW ENG. J. MED. 1428 (1998).

80. U.S. RENAL DATA SYS., *supra* note 52, at 69-83.

ent's age or medical condition. Persons who need continuing chronic dialysis may survive for years, but chances of significant rehabilitation are limited.⁸¹

Life on dialysis is, to put it mildly, onerous. To exist is possible, to thrive unusual, and to prosper almost unheard of.⁸² The dialysis patient must keep a strict diet: because excess protein, potassium, sodium, phosphorus, and water have no place to go, their intake must be severely restricted. Try a dialysis diet, and see what happens to your appetite. The dialysis patient is subjected to a daily, never-ending procession of needles, tubes, blood work, and injections. Even the relatively humane regimens of home dialysis require the presence of a floppy tube protruding from the midabdomen and the constant attention to cumbersome details. Marcia Campbell Marden has described life on dialysis:

A year ago I would not let you see me without mascara. Today you can view me three times a week without my pride. . . . I am dry, and always, always thirsty . . . I smell old and sick. And even Shalimar cannot cover the odor of dialysate . . . I am afraid . . . I am determined to escape this. I will not forget and I *will* not return.⁸³

From a patient's perspective, transplantation is the optimal treatment for ESRD.

Survival rates also demonstrate the superiority of transplantation as the preferred treatment option for ESRD. Among bona fide transplant candidates, excluding those older, sicker patients who are less likely to be offered the option of a transplant, receiving a kidney transplant reduces mortality by 33%.⁸⁴ Thus, from a medical perspective, transplantation is the optimal treatment for ESRD.

Since 1972, the federal government has funded both dialysis and transplantation for virtually all Americans with irreversible kidney failure.⁸⁵ Congress intended "to provide access to life-saving therapy for all who needed it where the costs of treatment were beyond the means of practically all individuals."⁸⁶ After assuming the financial burdens of ESRD therapy, the Health Care Financing Administration (HCFA) quickly ascertained that a successful transplant was the most cost-effective treatment for irreversible renal failure, and mandated its

81. Sheldon W. Tobe & John S. Senn, *Forgoing Renal Dialysis: A Case Study and Review of Ethical Issues*, 28 AM. J. KIDNEY DISEASES 147, 147 (1996).

82. The rate of suicide of dialysis patients is over 100 times that of the general population. See Cohen, *supra* note 16, at 38 n.110 (1989).

83. Marcia Campbell Marden, *Kidney Chronicles*, 25 AM. J. KIDNEY DISEASES 967, 967 (1995).

84. See Akinlolu O. Ojo et al., *Comparative Mortality Risks of Chronic Dialysis and Cadaveric Transplantation in Black End-Stage Renal Disease Patients*, 24 AM. J. KIDNEY DISEASES 59, 61 (1994).

85. Social Security Amendments of 1972, Pub. L. No. 92-603, § 2991, 86 Stat. 1329, 1463-64.

86. RETTIG & MARKS, *supra* note 25, at 30.

availability for all appropriate ESRD patients.⁸⁷ From a socioeconomic standpoint, transplantation is the optimal treatment for ESRD.

Given Professor Epstein's statement (with which we agree) that "UNOS rhetoric to one side, the benefits of organ transplants are quintessentially personal, not collective,"⁸⁸ we find it ironic that he would advance a class-based argument to the question of dialysis versus transplantation. Professor Epstein may be correct that government funding of ESRD treatment is largesse that inures, perhaps disproportionately, to the benefit of blacks. But once the government enters this arena, its erection of barriers to individual blacks' access to the preferred treatment is unacceptable precisely because they deny to those patients the "quintessentially personal" benefits of transplantation. Thus, again, our argument rests on this simple premise: any transplant candidate of any race or gender, in the absence of contravening medical circumstances, should have roughly the same access to a cadaveric kidney as any other candidate, and government allocation policy should reflect that goal.

It was clear to us in 1993, and remains so today, that although the issue is complex, the use of HLA matching as the primary determinant of cadaveric kidney allocation contributes significantly to the lowered access of black patients. Indeed, the experience with the mandatory sharing required for zero-mismatched kidneys demonstrates that such policies result in a profound redistribution of kidneys away from black transplant candidates, a result acknowledged even by proponents of the policy.⁸⁹ The underlying problem is an acute shortage of donor kidneys, which combines with the intractable demographic fact that a disproportionately black waiting list must chase a predominantly white donor population. Given a nationwide pool of potential recipients, donated kidneys are much more likely to match white transplant candidates.⁹⁰ These conditions have not changed

87. See generally R.W. Evans, *Organ Transplantation and the Inevitable Debate as to What Constitutes a Basic Health Care Benefit*, in CLINICAL TRANSPLANTS 1993, at 359 (J. Michael Cecka & Paul I. Terasaki eds., 1994).

88. EPSTEIN, *supra* note 1, at 275.

89. See Gjertson et al., *supra* note 15, at 1035; Bruce Barger et al., *The Impact of the UNOS Mandatory Sharing Policy on Recipients of the Black and White Races: Experience at a Single Renal Transplant Center*, 53 TRANSPLANTATION 770, 770 (1992).

90. Because a person's HLA antigens are determined by her genetic background, they are highly likely to segregate by race. Thus, it is generally accepted that any algorithm based on high-grade matching will, to some extent, limit interracial transplantation. See Velta A. Lazda, *The Impact of HLA Frequency Differences in Races on the Access to Optimally HLA-Matched Cadaver Renal Transplants*, 53 TRANSPLANTATION 352, 352 (1992). An analysis by race of the National Marrow Donor Program, involving 1.6 million potential donors, indicated that from a large, predominantly Caucasian donor pool, 77% of whites but only 18% of blacks could expect to make a match. See Patrick G. Beatty et al., *Impact of Racial Genetic Polymorphism on the Probability of Finding an HLA-Matched Donor*, 60 TRANSPLANTATION 778, 780-81 (1995). Surprisingly, due to extensive heterogeneity in HLA among black Americans, even a completely black donor pool would produce matches for only 61% of black patients. See *id.* The authors of the study therefore concluded that an increase in minority donation would not alleviate the

since our initial article. In fact, the waiting list has grown much larger⁹¹ with no corresponding increase in donors, and waiting times have multiplied. And although black donation has improved (from 8% in 1990 to 11.4% in 1995—a figure close to that of African Americans in the general population from which donors come), black patients still make up fully a third of listed ESRD patients who need donated kidneys.⁹² Increased black donation, though an important remedial avenue to pursue, has not and will not fix the problem.

The racial disparity in kidney transplantation is an issue that has long plagued UNOS. Among other things, UNOS has begun to consider how allocation based on HLA matching contributes to the problem. A report issued by the UNOS Histocompatibility Committee in 1995 concluded that “[b]lack recipients wait longer due to biologic factors” including sensitization, blood type, and “some HLA antigen types that are common in blacks but may not be common in the donor population.”⁹³ The report further notes that “[e]ven though blacks donate organs in proportion to the general population, the fact that most donors are Caucasian may disadvantage those black patients who have HLA antigens that are rare in the Caucasian population.”⁹⁴ In response to the accumulating data, UNOS modified its position in 1995 by implementing a more equity-based system, one that retains the importance of complete HLA matches but de-emphasizes the significance of “partial” matches while increasing the relative value of points for waiting time.⁹⁵ We applaud these changes as steps in the right direction, indeed as steps we urged be taken in our original article.⁹⁶ The result has been a slightly greater percentage of kidneys for African American patients, while overall graft survival has continued to improve.⁹⁷ But the statistics are still dismal, and much remains to be done.

problem and that the key to increasing access was improved technologies allowing transplantation from HLA-mismatched donors. *See id.* at 782.

91. As of July 31, 1997, there were 36,559 kidney patients on the waiting list. *See* 2 UNOS BULLETIN, ISSUE 8 (Aug. 1997).

92. *See* Harper & Rosendale, *supra* note 67, at 71, 84.

93. UNOS Histocompatibility Committee, *The National Kidney Distribution System: Striving for Equitable Use of a Scarce Resource*, UNOS UPDATE, Aug. 1995, at 31, 32.

94. *Id.* at 32. Another study found that in a system in which quality of HLA match accounted for roughly 90% of allocation points, points were being assigned for partial match levels associated with graft survival equal to or worse than the national average. *See* Douglas J. Norman et al., *Cadaveric Kidney Allocation in the United States: A Critical Analysis of the Point System*, 27 TRANSPLANTATION PROC. 800 (1995).

95. *See generally* UNOS, UNOS UPDATE, Dec. 1994, at 18.

96. *See* Ayres et al., *supra* note 5, at 846-47.

97. *See* Andrea A. Zachary et al., *Local Impact of 1995 Changes in the Renal Transplant Allocation System*, 63 TRANSPLANTATION 669, 671 (1997); *cf.* Steven Katznelson & J. Michael Cecka, *Immunosuppressive Regimens and Their Effects on Renal Allograft Outcome*, in CLINICAL TRANSPLANTS 1996, *supra* note 66, at 361, 361-71.

V. OUTLOOK FOR THE FUTURE

The wonder of kidney transplantation is its life-changing effect on the fortunate patient who can stop dialysis treatments and resume a normal life. The tragedy of transplantation is that it is available only to the few. Donation based on altruism seems to have stalled.⁹⁸

Professor Epstein cogently analyzes the prospects of a successful market on the supply side, noting that the idea of a futures market, touted by other scholars,⁹⁹ is fraught with hazards.¹⁰⁰ Instead, his preferred solution, one which we find promising, is a market in unmatched live donor kidneys.¹⁰¹ Ironically, such a market could thrive only if HLA matching is deemed relatively unimportant as a determinant of successful transplant outcomes—the very argument we made in 1993 and believe the evolving medical literature of today supports even more strongly. This is another example of technology outstripping tradition. Conventional wisdom held that transplants from mismatched family members or unrelated live donors would result in very low success rates, such that only complete or half matches were considered sufficient to justify the risk of removing a kidney from an otherwise healthy donor. Newer research by scholars known for their heretofore resolute commitment to the importance of matching has demonstrated that no difference can be ascertained in outcomes at three years posttransplant between completely mismatched, unrelated donor-recipient pairs and most family member pairs.¹⁰² And because those results are superior to those of even complete matches in cadav-

98. In 1990, 9878 cadaveric kidneys were made available for transplant in the United States; that number has gone up incrementally, but as of 1995 there were still only 11,818 kidneys available from cadaveric donors. See UNITED NETWORK FOR ORGAN SHARING, UNOS UPDATE, Summer 1997, at 35 (UNOS Scientific Registry data).

99. See, e.g., Cohen, *supra* note 16.

100. See EPSTEIN, *supra* note 1, at 249-53.

101. See *id.* at 253-61.

102. See Paul I. Terasaki et al., *High Survival Rates of Kidney Transplants from Spousal and Living Unrelated Donors*, 333 NEW ENG. J. MED. 333 (1995). This striking research is capsulized in the following chart:

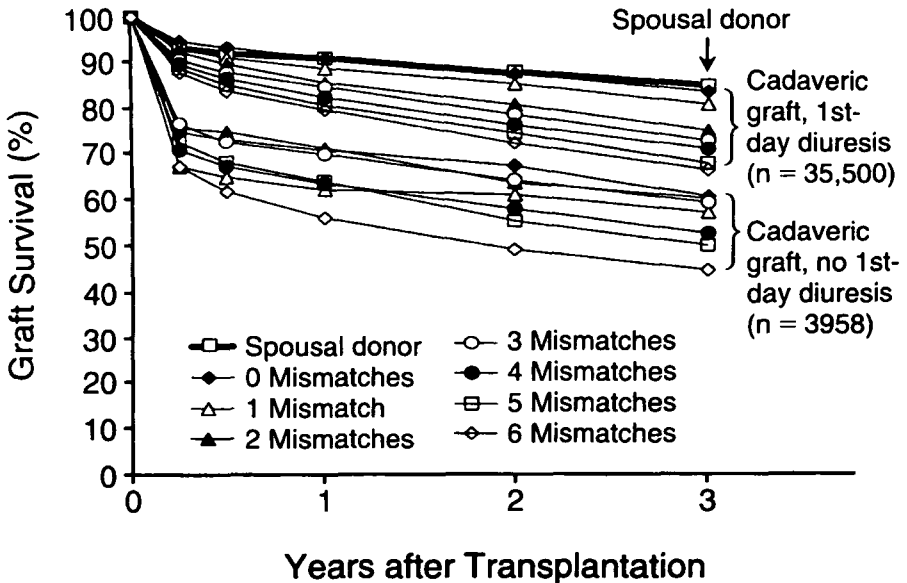
eric kidney transplants,¹⁰³ the case for unrelated living donor transplantation becomes even more compelling.

In most transplant centers in recent years, it has become commonplace to use live donors, when available, who are emotionally rather than genetically linked to the ESRD patient. This practice, of course, also demonstrates the declining role of matching as a key to transplant success. Professor Epstein's preferred remedy to the shortage issue—the market in live donor kidneys¹⁰⁴—would replace the emotional incentive to donate with a financial one, but the science that makes such a market possible is already in place thanks to the rapid development of effective immunosuppression. Thus, we are intrigued by Professor Epstein's optimism that such a market might work to increase supply; at least it is an avenue worth exploring.

We must part company with Professor Epstein, however, on the demand side. We continue to believe that the queue for receiving a transplant must operate equitably, and that the concept of equity must exclude considerations of wealth.¹⁰⁵ Thus it seems to us inevitable

FIGURE 3. SURVIVAL OF FIRST CADAVERIC GRAFTS ACCORDING TO URINE FLOW ON THE FIRST DAY.

THE GRAFTS WERE FURTHER GROUPED ON THE BASIS OF THE NUMBER OF HLA-A, B, AND DR MISMATCHES. THE SPOUSAL-DONOR GROUP IS INCLUDED FOR COMPARISON.



Terasaki et al., *supra*, at 335. Copyright © 1995 Massachusetts Medical Society. All rights reserved, reproduced with permission.

103. See *id.* at 334.

104. See EPSTEIN, *supra* note 1, at 253-61. Indeed, Epstein may underestimate the potential benefit of such a market, at least as to kidney transplantation, by exaggerating concerns that suitable matches may not be found between random donors and recipients. See *id.* at 254.

105. See *supra* text accompanying notes 18-23.

that some sort of centralized (probably government-run) entity must facilitate the allocation process, though we are willing to hope that the task might be greatly eased if a commercial market or another remedy dramatically improved the supply. Moreover, the current network of organ procurement organizations (OPOs), which now act as conduits for funds passing from Medicare to harvesting hospitals, might also be utilized as conduits to compensate live donors, with the kidneys to be placed in a pool for the most suitable recipient.

Whatever distributive choices are made, and regardless who makes them, it is essential that the system be responsive to constantly changing technologies. Professor Epstein faults UNOS for what he perceives as a government monopolist pandering to political interests, while at the same time extolling the superiority of the market in terms of responsiveness to technological progress. We perceive UNOS's point system modifications, along with its ongoing inquiries into the racial disparity problem in light of constantly evolving data,¹⁰⁶ to be evidence that even an institution acting under congressional authority can respond in a rapid but rational way to emerging medical information.¹⁰⁷

Technological progress on the horizon may in fact hold the promise of alleviating the organ shortage in a completely different fashion, by decreasing our exclusive reliance on human sources for donation. Some would trumpet xenotransplantation—animal to human transplants—as the frontier of the future, one that could provide a relatively unlimited source of organs for transplantation. At this point, significant immunologic barriers to successful animal to human transplantation remain, but major strides are being made scientifically in defining the human immune response to xenografts. An even more promising approach may be the development of molecular techniques known collectively as cloning. It may soon be possible, for example, to induce an animal such as a pig to grow kidneys that express human histocompatibility antigens, and not be subject to xenograft rejection. All these promising technologies demonstrate that we have the poten-

106. For example, see UNOS's announcement last summer of a pilot study that will examine the effect of a more sophisticated matching system on the availability of cadaveric kidneys for racial minorities. UNOS Press Release, *New Method of Matching Donated Kidneys May Mean More Transplants for Minorities* (visited Mar. 11, 1998) <http://www.unos.org/Newsroom/archive_newsrelease_0625976.htm>.

107. Professor Epstein himself acknowledges that this is a plausible characterization: "This modification of UNOS rules could be justified as an effort to overcome institutional rigidity and to meet the charge that UNOS guidelines cannot move fast enough to respond to changes in technology." EPSTEIN, *supra* note 1, at 276.

We are convinced that UNOS's personnel operate in good faith to meet their statutory and regulatory obligations and that UNOS's committee structure is a viable means of responding to technological change in various aspects of organ transplantation. Moreover, we imagine that Professor Epstein would agree with us that UNOS, made up as it is of citizens, patients, and transplant professionals, is more capable of appropriately rapid reaction to evolving technology than a traditional government bureaucracy like HHS.

tial to grow beyond a transplant system reliant solely on matching human organs between donors and recipients.¹⁰⁸

In the short term, however, we are left with an organ shortage, and a corresponding difficulty in allocation of organs.¹⁰⁹ We argued back in 1993 that a proper accommodation between the efficiency and equity goals of the cadaveric kidney allocation system could be best achieved by maintaining a distributional advantage for very well-matched kidneys (where the medical benefits were well documented) and by rectifying the disadvantage this visits on those patients with rare antigens by awarding them points that give them improved access to other than well-matched kidneys.¹¹⁰ At the least, we argued that medical evidence did not support the use of partial matching as a major criterion for distribution and that waiting time should factor more heavily.¹¹¹ The changes UNOS made to the point system in 1995 essentially followed the second route, along with expanding the definition of a complete match. Those changes resulted in more African American candidates receiving well-matched kidneys (from 1.9% in 1994 to 4.7% in 1995),¹¹² though white recipients continue to be the overwhelming beneficiaries of the points given for excellent matches.¹¹³ Meanwhile, transplants of partially matched kidneys declined in both the black and white populations.¹¹⁴ Although the vast majority of transplants for African American patients are still poorly matched, the success rates continue to improve.¹¹⁵ We therefore

108. Within the realm of HLA matching, technology marches on as well. There have been remarkable advances in understanding HLA matching in recent years, such that it is now possible to define HLA antigens at the molecular, rather than cellular, level. See Steven K. Takemoto et al., *HLA Matching: Maximizing the Number of Compatible Transplants*, in *CLINICAL TRANSPLANTS* 1993, *supra* note 87, at 521 [hereinafter Takemoto, *HLA Matching 1*]; Steven K. Takemoto, *HLA Amino Acid Residue Matching*, in *CLINICAL TRANSPLANTS* 1996, *supra* note 66, at 397 [hereinafter Takemoto, *HLA Matching 2*]. Thus, thousands rather than hundreds of antigen specificities may be identified and matched. But the cost of greater specificity in identification is a reduction in the likelihood of finding true matches between unrelated individuals. Matching becomes, then, an even less useful tool in allocating organs.

A new approach is to define broad groups with permissible molecular mismatches in such a way as to make donor-recipient matching easier. This is called cross reactive epitope-group (CREG) classification or residue matching. See Takemoto, *HLA Matching 1*, *supra*, at 521. The broader the groups, the more likely it is that racial barriers will fall. However, as with the present matching scheme, the reality is that excellent outcomes with cadaveric transplants only accrue to extremely well-matched pairs, regardless of the way one defines "matching." See Takemoto et al., *supra* note 15, at 834; Yoshinobu Hata et al., *HLA Matching*, in *CLINICAL TRANSPLANTS* 1996, *supra* note 66, at 381.

109. The impact of recent HHS proposed changes in organ allocation policies, which would guarantee priority for the sickest patients, on minority access to cadaver kidneys has yet to be addressed. Elizabeth Neus, *HHS Asks Senate to Remove Organ Transplant Proposal from Huge Spending Bill*, Gannett News Serv., Sept. 10, 1998, available in 1998 WL 5634531.

110. See Ayres et al., *supra* note 5, at 844.

111. See *id.* at 846-67.

112. See Hata et al., *supra* note 108, at 388.

113. Over 14% of white candidates receive well-matched kidneys. See *id.*

114. See *id.* at 391.

115. J. Michael Cecka, *The UNOS Scientific Renal Transplant Registry*, in *CLINICAL TRANSPLANTS* 1996, *supra* note 66, at 1, 2.

maintain that any proposal that would mandate more extensive reliance on matching, given the predominantly Caucasian donor pool, will threaten access for the majority of African American ESRD patients.¹¹⁶ Yet we would not propose a pure equity-based, first-come, first-served queue; to do so would ignore the small but significant advantage in terms of outcome for excellent matches.¹¹⁷ Instead, we reaffirm our earlier position that a system can best achieve both equity and efficiency by a careful calibration: combine the benefits of excellent matching for the few recipients able to access such matches with a mechanism to enhance equity for those unable to match the donor population.¹¹⁸ Most importantly, the system must have the flexibility to evolve in light of changing empiricism, including improved clinical management of recipients, better histocompatibility testing, or (best of all) true resolution of the donor shortage.

VI. CONCLUSION

Professor Epstein is to be congratulated for an insightful, remarkable critique of organ transplantation in the United States. However, we find the situation to be less bleak, and much more complicated, than he portrays: amazing technological advances have brought us to this point, and promise to take us farther. The government's role is to ensure that no one is left behind. As Marcia Campbell Marden, the former dialysis patient, observed after her own kidney transplant: "This kidney has made my own bridge from Heaven to Earth [T]his is the richest travel I have taken. I have seen the sights with brilliant clarity as never before. Bartimaeus recalled. This journey is not over yet. . . . This was an enchanted time."¹¹⁹

116. The "trickle-down" argument—that better matching will lead to more successful transplants such that fewer patients will be listed for retransplant which further depletes the pool—is an unsatisfactory response to the problem as well. The numbers speak for themselves: over 35,000 hopeful recipients annually chase a pool of approximately 10,000 kidneys. See *supra* notes 91 and 98. There will always be white candidates out there who match better.

117. Our critics have argued that our emphasis on the ability of immunosuppressants to make non-HLA-matched kidney transplants a viable allocative option ignores the negative side effects of that therapy. See Cohen & Michelsen, *supra* note 21, at 151-52. Even well-matched recipients take the same drugs, usually in the same doses, as those recipients completely mismatched with their donor. A high-grade match may confer better outcome, but it does not confer freedom from immunosuppressive drugs and their side effects, as Epstein implies. See EPSTEIN, *supra* note 1, at 274.

118. See Ayres et al., *supra* note 5, at 848 (explaining how "[t]he mode of allocating cadaveric kidneys may alter the number of kidneys that are harvested" by impacting the incentives of the harvesting doctor).

119. Marden, *supra* note 83, at 970.