

WHEN ALTRUISM IS NOT ENOUGH: THE WORSENING ORGAN SHORTAGE AND WHAT IT MEANS FOR THE ELDERLY

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This article, presented by Dr. Sally L. Satel in the 2007 Ann F. Baum Memorial Elder Law Lecture at the University of Illinois College of Law, discusses the dynamics of allocating the scarce supply of transplantable organs and the various schemes for doing so that have developed over the years. Upon providing the historical context for dialysis and organ donation, Dr. Satel and Dr. Hippen examine the specific issue of renal failure as a major problem affecting older people and explain how donated

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kidneys can ensure better clinical outcomes for the affected elderly compared with dialysis. The authors consider the implications of organ donation for Medicare, which funds the costly End Stage Renal Disease program. The authors also evaluate current efforts to restructure the allocation system of donated kidneys that tends to discriminate against older candidates on the basis of age. Dr. Satel and Dr. Hippen conclude that allowing some form of compensation for organ donors would be an effective way to increase the supply of transferable kidneys.

I. Introduction

Organ transplantation is one of the crowning achievements of medical science. Yet from 1954, the year of the first renal transplant, to the present, there have never been enough organs to meet the need.¹ In fact, the gap between supply and demand has widened inexorably over time, a pattern one could begin to document with depressing accuracy in 1987, the year the national registry of patients in need of organs was first published.² Of all transplantable organs—hearts, livers, lungs, pancreas—the shortage of kidneys is most acute. More than three-quarters of the wait-list population comprises people suffering from renal failure, also called end-stage renal disease (ESRD).³ Strikingly, as the list continues to grow, most of its expansion over the last decade has been due to the addition of patients older than sixty-five years of age.⁴

Consequently, the elder population claims the largest share of kidneys. Yet because the wait for a deceased donor kidney is years long, an elderly patient might derive only a few good years from a transplanted organ before dying from other diseases related to aging. In contrast, younger recipients enjoy more years to live in terms of their natural longevity as well as the survival of the transplanted kidney—and with half of all cadaver kidneys and living kidneys functioning longer than ten years and nineteen years, respectively, the ad-

1. See Francis L. Delmonico, *What Is the System Failure?*, 69 KIDNEY INT'L 954 (2006).

2. Ronald M. Davis, *Meeting the Demand for Donor Organs in the U.S.*, 319 BRIT. MED. J. 1382 (1999), available at <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1117120>.

3. See Organ Procurement & Transplantation Network, *Organ by Waiting Time*, <http://www.optn.org/data> (select "National Data" on left; then select "Waiting List" category; then select "Organ by Waiting Time" report) (last visited Feb. 12, 2007) [hereinafter *Organ by Waiting Time*].

4. Jack J. Curtis, *Ageism and Kidney Transplantation*, 6 AM. J. TRANSPLANTATION 1264 (2006).

ditional years added to patients' lives are not trivial.⁵ This reality has raised the controversial issue of whether older people should have the same access to high-quality organs as younger candidates, and whether the oldest among them should be considered transplant candidates at all. Questions abound. Is a donor kidney being squandered when it is given to an elderly person rather than to a younger candidate? Should an older patient instead remain on dialysis? Should he be given an organ of marginal quality on the assumption that it will last "long enough"? In distributing what is considered to be a finite "public resource," and with the knowledge that any system of allocation must deny some potential beneficiaries, medical experts and society continue to ask these questions, which capture the anguished deliberations that unfailingly accompany scarcity.

For more than a decade after the advent of dialysis technology in the 1960s, access to dialysis was tightly guarded until the turmoil over rationing abated in 1972, with the establishment of the Medicare End Stage Renal Disease program, a comprehensive federal entitlement for coverage of dialysis therapy. Now that long-term dialysis is available to nearly everyone with renal failure, it is organs that are in scant supply. And how could it have been otherwise once life-prolonging technology was able to keep people alive long enough to be transplanted?

In this article, we discuss the epidemiology of ESRD, a condition treated with either dialysis or transplantation. We describe how the relentless growth in the number of aging patients is affecting current ideas and policies for allocating deceased-donor kidneys. Furthermore, we show how the organ shortage is the paradoxical product of increased access to long-term dialysis and consider potential remedies for the enlarging chasm between demand and supply, while paying special attention to the current and future plight of elderly transplant candidates. After reexamining the basic motive of altruism underlying the organ procurement system in the United States, we conclude the article with an overview and analysis of novel approaches to organ procurement, such as the introduction of incentives for living individuals to relinquish a kidney. In so doing, we close a circle con-

5. U.S. RENAL DATA SYS., 2006 ANNUAL DATA REPORT: ATLAS OF CHRONIC KIDNEY DISEASE END-STAGE RENAL DISEASE IN THE UNITED STATES 152 (2006), available at <http://www.usrds.org/atlas.htm> [hereinafter 2006 ANNUAL DATA REPORT].

necting the introduction of dialysis in the 1960s to the severe kidney shortage that prevails in 2007—and we reflect on the sad irony that while details have changed, the basic challenge of assigning scarce resources remains the same.

II. Background

A. Epidemiology of End-Stage Renal Disease (ESRD)

In 2004, 336,000 ESRD patients were receiving dialysis.⁶ The mean age of patients who began dialysis in 2004 was sixty-five.⁷ Almost half the population of dialysis patients was over age sixty-five, and one-fifth was older than seventy-five.⁸ Notably, this latter subset accounted for the steepest rate of growth between 1994 and 2004; by 2004, those over sixty-five represented one in every four new cases.⁹ The upstream pool feeding the cohort of end-stage patients is a much larger population of people with compromised kidney function, estimated to total between eight million and ten million, who are at risk for deteriorating to the point of failure—and thus in need of dialysis or transplant.¹⁰ Epidemiologists estimate that by 2010, some 520,000 people in the United States will be on dialysis, up from approximately 336,000 patients in 2004; by 2015, more than 700,000 may have ESRD.¹¹

For many patients, a transplant confers a significant survival advantage over remaining on dialysis. Roughly one out of every five patients on dialysis is also on the national transplant list, waiting for a kidney from a deceased donor.¹² The reasons for the absence of the

6. *Id.* at 68.

7. E-mail from Paul W. Eggers, Program Dir. for Kidney & Urology Epidemiology, Nat'l Inst. of Diabetes & Digestive & Kidney Diseases, to Sally L. Satel, Resident Scholar, Am. Enter. Inst. (Jan. 12, 2007, 14:46 EST) (on file with author).

8. U.S. RENAL DATA SYS., 2006 ANNUAL DATA REPORT REFERENCE TABLES 112 tbl.D.11 (2006), available at <http://www.usrds.org/reference.htm> [hereinafter REFERENCE TABLES 2006].

9. 2006 ANNUAL DATA REPORT, *supra* note 5, at 80 fig.2.34.

10. Josef Coresh et al., *Prevalence of Chronic Kidney Disease and Decreased Kidney Function in the Adult US Population: Third National Health and Nutrition Examination Survey*, 41 AM. J. KIDNEY DISEASES *11 (2003) (on file with The Elder Law Journal).

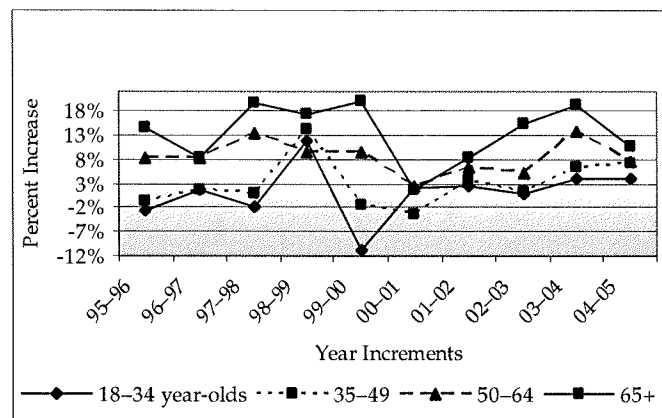
11. David T. Gilbertson et al., *Projecting the Number of Patients with End-Stage Renal Disease in the United States to the Year 2015*, 16 J. AM. SOC'Y NEPHROLOGY 3736, 3740 fig.5 (2005).

12. See ORGAN PROCUREMENT & TRANSPLANTATION NETWORK & SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS, U.S. DEP'T OF HEALTH & HUMAN SERVS., KIDNEY AND PANCREAS TRANSPLANTATION IN THE UNITED STATES, 1996–2005 (2006), available at http://www.ustransplant.org/annual_reports/current/Chapter_IV_AR_CD.htm?cp=5 [hereinafter KIDNEY AND PANCREAS TRANSPLAN-

remaining majority of dialysis patients from the list are not clear. It is possible that they are medically unsuitable, were rejected for listing after being referred by their physician, were never referred, or declined referral. In any event, due to an increasing willingness on the part of transplant professionals to consider and list older patients for transplantation, more and more elderly candidates are being added to the waiting list for a deceased donor transplant, as Figure 1 shows. For example, from 1995 to 2004 the number of young adults ages eighteen to thirty-four increased by 12%, while those between the ages of fifty and sixty-four increased by 72%, and those older than sixty-five increased by 134%.¹³ Consequently, the rate at which the elderly are added to the waiting list has far outstripped the rate at which kidneys are supplied.

Figure One

Percent Increases of Age Groups on the UNOS Kidney Waiting List



As of February 2, 2007, 73,820 people were waiting for a kidney, according to the United Network for Organ Sharing (UNOS), which maintains the national registry of transplant candidates.¹⁴ In big cities,

TATION]. Of approximately 290,000 patients on dialysis in 2002, about 50,000 were on the kidney transplant waiting list. Global Dialysis, Dialysis Statistics, <http://www.globaldialysis.com/stat.asp> (last visited Feb. 12, 2007).

13. See KIDNEY AND PANCREAS TRANSPLANTATION, *supra* note 12, at 5 fig.1.

14. Organ Procurement & Transplantation Network, Overall by Organ, <http://www.optn.org/data> (select "National Data" on left; then select "Waiting List" category; then select "Overall by Organ" report) (last visited Feb. 12, 2007).

where the ratio of needy patients to available organs is highest, the waiting time for a kidney can exceed eight years.¹⁵ Time waiting is spent on dialysis, a procedure in which the patient's blood is circulated through a machine that purifies it and returns it to the body. Patients dependent upon dialysis typically visit a treatment center three times a week, for four hours per visit. The process ends when they receive a transplant or die, whichever comes first. In 2006, the most recent year for which complete transplant data are available, only 15,721—or only 21% of those waiting—received kidneys.¹⁶ Meanwhile, 3531 died waiting, and the grim picture is guaranteed to worsen.¹⁷ Projections estimate that by 2010, the median waiting time will be at least ten years, a period of time longer than most adults are able to survive on dialysis, especially the vast majority of patients older than the age of sixty-five.¹⁸

People older than age sixty-five are particularly vulnerable to the medical consequences of long-term dialysis, particularly due to aggravation of the cardiovascular diseases already widespread among elderly patients.¹⁹ Three-quarters of patients between the ages of sixty-five and seventy-four are still alive one year after beginning dialysis, but the survival probabilities decline quickly thereafter:²⁰ at two years, 60% are still alive; at five years, 26% are still alive; and at ten years, only about 5% are still alive.²¹ By contrast, eight of nine patients between the ages of twenty and forty-four survive one year after beginning dialysis, and half of the cohort are still living after ten years

15. See Organ Procurement & Transplantation Network, New York: Organ by Waiting Time, <http://www.optn.org/data> (select "State Data" on left; then select "New York"; then select "Waiting List" category; then select "Organ by Waiting Time" report) (last visited Feb. 12, 2007) (indicating that of 6085 patients on the waiting list as of February 2, 2007, there were 1096 with a waiting time of more than five years in the state of New York).

16. Organ Procurement & Transplantation Network, Transplants by State, <http://www.optn.org/data> (select "National Data" on left; then select "Transplant" category; then select "Transplants by State" report) (last visited Feb. 12, 2007).

17. See generally Vincent Casingal et al., *Death on the Kidney Waiting List—Good Candidates or Not?*, 6 AM. J. TRANSPLANTATION 1953, 1953–55 (2006) (explaining that many patients who die while waiting for kidneys would not have been poor transplant candidates).

18. Jay L. Xue et al., *Forecast of the Number of Patients with End-Stage Renal Disease in the United States to the Year 2010*, 12 J. AM. SOC'Y NEPHROLOGY 2753, 2754 (2001).

19. Herwig-Ulf Meier-Kriesche et al., *Effect of Waiting Time on Renal Transplant Outcome*, 58 KIDNEY INT'L 1311, 1313 (2000).

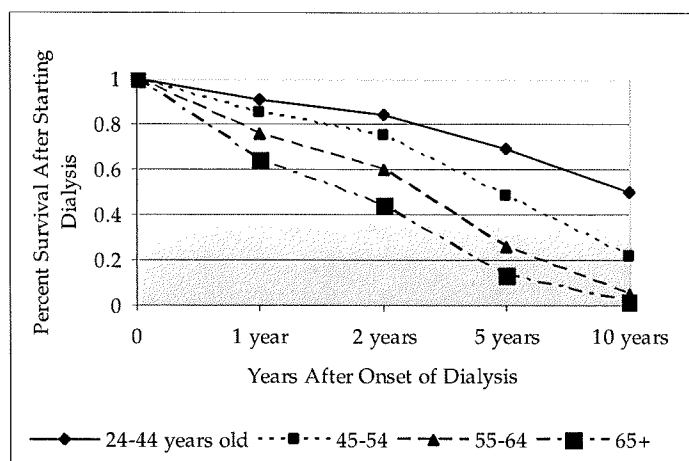
20. REFERENCE TABLES 2006, *supra* note 8, at 296–301 tbls.1.3–1.7.

21. *Id.* at 298 tbl.1.4, 300 tbl.1.6, 301 tbl.1.7.

of dialysis, as Figure 2 demonstrates.²² Clearly, a year of waiting time for a twenty-five-year-old patient on dialysis is not the physiological equivalent of a year of waiting time for a sixty-five-year-old. Indeed, the physiologically stressful effects of dialysis plus ubiquitous diseases among the elderly may explain in large part why only 5% of all patients over sixty-five are listed by UNOS: the rest are not healthy enough to qualify to become transplant candidates in the first place.²³

Figure 2

Survival on Dialysis over Time by Age



Source: UNITED STATES RENAL DATA SERVICE, 2006 ANNUAL REPORT, http://www.usrds.org/2006/ref/l_survival_06.pdf

Approximately 100,000 patients will be on the waiting list for a donor kidney by 2010 if the current rate of listing remains steady at 20% of end-stage patients.²⁴ Elderly transplant candidates are the fastest-growing group of potential recipients, and because they are the most likely to be suffering from advanced cardiovascular disease, the increasingly longer waiting time for donor organs means that they are at the highest risk of dying while waiting for a kidney compared to other age groups. The waiting time for an organ will exceed the me-

22. *Id.* at 296 tbl.1.3, 301 tbl.1.7.

23. U.S. RENAL DATA SYS., 2005 ANNUAL DATA REPORT: ATLAS OF END-STAGE RENAL DISEASE IN THE UNITED STATES 99 tbl.4.c (2005), available at http://www.usrds.org/atlas_2005.htm.

24. Xue et al., *supra* note 18, at 2756.

dian lifespan of virtually every elderly candidate on the list. Thus, although the growing disparity between the demand and supply of cadaver kidneys affects all renal transplant candidates, the burden is particularly heavy upon older candidates.

B. Economic Costs of Renal Disease

The economic cost to the federal government of end-stage care mirrors the human cost. In 2004, it totaled \$16.3 billion, of which \$922 million, or about 6%, went to the cost of kidney transplantation.²⁵ Patients with renal failure make up less than 1% of Medicare recipients but consume slightly less than 7% of the Medicare budget.²⁶ In 2005, \$2 billion alone went toward reimbursement for recombinant erythropoietin,²⁷ a hormone normally synthesized endogenously by functioning kidneys, administered as a medication responsible for stimulating the production of red blood cells in the bone marrow. By 2010, the total cost to the federal government is expected to increase to \$28 billion.²⁸

Elderly patients with renal failure face a daunting financial situation. Dialysis, a manifestly inferior therapy compared to transplantation as measured by both quality and quantity of life, is reimbursed in entirety by Medicare or Medicaid.²⁹ The cost of procuring deceased-donor organs and the cost of transplant surgery are reimbursed by Medicare, but only 80% of the costs of immunosuppression medications necessary to sustain the transplant are reimbursed by Medicare, and then for only three years after transplantation.³⁰ Consequently, transplant recipients may be responsible for several thousand dollars per year in out-of-pocket expenses simply to purchase their immuno-

25. 2006 ANNUAL DATA REPORT, *supra* note 5, at 29.

26. 2006 ANNUAL DATA REPORT, *supra* note 5, at 207 ("ESRD program costs continue to rise and . . . now exceed \$20 billion—6.7 percent of the total Medicare budget"); see also CTRS. FOR MEDICARE & MEDICAID SERVS., DEP'T OF HEALTH & HUMAN SERVS., SUMMARY OF THE ESRD NETWORK PROGRAM 1 (2006), available at <http://www.cms.hhs.gov/ESRDNetworkOrganizations/Downloads/ESRDNetworkProgramBackgroundpublic.pdf> (noting that there were 321,539 patients in the ESRD program at the end of 2004).

27. Robert Steinbrook, *Medicare and Erythropoietin*, 356 NEW ENG. J. MED. 4, 4 (2007).

28. Xue et al., *supra* note 18, at 2757.

29. Steinbrook, *supra* note 27.

30. See HEALTH CARE FIN. ADMIN., THE FED. MEDICARE AGENCY, MEDICARE COVERAGE OF KIDNEY DIALYSIS AND KIDNEY TRANSPLANT SERVICES 35 (2002), available at <http://www.medicare.gov/publications/pubs/pdf/esrdcoverage.pdf>.

suppression medications, to say nothing of medications for hypertension, diabetes, elevated cholesterol, osteoporosis, and a host of other potentially fatal afflictions that can accompany kidney transplantation. After three years, patients without private insurance or a separate pharmaceutical plan are responsible for the entire cost of these medications, which typically approaches \$10,000 to \$15,000 per year.³¹ Retired elderly patients on a fixed income may find the \$2000 to \$3000 Medicare co-payment for immunosuppression alone insurmountable, to say nothing of potentially being responsible for a larger fraction of the cost after the three-year Medicare reimbursement period has passed.

Perversely, the unintended consequence of the current Medicare reimbursement system is that it may be in the financial best interest of a resource-strapped elderly patient to remain on dialysis rather than to receive a kidney transplant, due to the financial burden of immunosuppression. This is despite the fact that in most circumstances, transplantation confers a greater quantity and better quality of life, and that for the federal government, the cost of dialysis and attendant complications far exceeds the cost of transplantation.³² The U.S. Renal Data Service estimates that the average annual expenditure for a patient on dialysis is \$66,650.³³

C. Can Prevention Lower Costs?

What is the prospect that preventive medicine will be able to head off the cost of dialysis, transplants, and overall Medicare expenditures for end-stage disease? Counterintuitive as it may seem, the answer is that preventive medicine could actually make things worse. Though some have attributed the rising rates of kidney failure and demand for transplantation to the medical community's failure to address other medical problems,³⁴ the truth may be exactly the oppo-

31. *See id.*

32. Gabriel C. Oniscu et al., *How Great Is the Survival Advantage of Transplantation over Dialysis in Elderly Patients?*, 19 NEPHROLOGY DIALYSIS TRANSPLANTATION 945, 950 (2004).

33. 2006 ANNUAL DATA REPORT, *supra* note 5, at 208–09 fig.11.8. Annual expenditures for patients with ESRD varies depending on the dialysis modality (hemodialysis versus peritoneal dialysis), baseline health status of the patient, and cost of treatment of comorbid conditions. *Id.*

34. Delmonico, *supra* note 1, at 955.

site.³⁵ As it stands now, the vast majority of people with kidney disease die from complications of heart disease and stroke before ever progressing to renal failure. But as the treatment of heart attacks, strokes, hypertension, and diabetes is improving, those afflicted are living longer—long enough to develop renal failure. It is the manifest success of these treatments that is now permitting a small fraction of the population with advanced kidney disease to survive the cardiovascular burdens of hypertension and diabetes—and thereby live long enough so that their kidney disease can progress to kidney failure.³⁶

Kidney disease remains a burden that disproportionately affects the poorest segments of society,³⁷ and it is plausible to suppose that at least part of that burden is due to inadequate screening of and care for important risks.³⁸ But this fails to explain the fact that it is the *elderly* who make up the majority of new patients with kidney failure. In short, the “epidemic” of ESRD among the elderly represents the unintended consequence of successful medical interventions in cardiovascular disease.³⁹ To avert development of diseases that heighten risk for kidney failure in the first place, prevention efforts need to begin early in life. However, such so-called primary intervention efforts are notoriously challenging, and any benefits that might accrue will be delayed for decades. The current woeful deficit will be untouched.

Advances in immunosuppressive medications necessary for sustaining a kidney transplant have only expanded the fraction of patients with ESRD who might benefit from dialysis. Few groups have derived more potential benefit from such advances than the elderly, leading the transplant community to ask the question, “How old is too old for transplantation?”⁴⁰ The rising prevalence of renal failure and

35. See Benjamin Hippen, Letter to the Editor, *Preventive Measures May Not Reduce the Demand for Kidney Transplantation. There Is Reason to Suppose This Is Not the Case*, 70 KIDNEY INT'L 606 (2006).

36. *Id.* at 607.

37. See Nicholas Drey et al., *A Population-Based Study of the Incidence and Outcomes of Diagnosed Chronic Kidney Disease*, 42 AM. J. KIDNEY DISEASES 677 (2003); Eric W. Young et al., *Socioeconomic Status and End-Stage Renal Disease in the United States*, 45 KIDNEY INT'L 907 (1994).

38. Annamaria T. Kausz et al., *General Medical Care Among Patients with Chronic Kidney Disease: Opportunities for Improving Outcomes*, 16 J. AM. SOC'Y NEPHROLOGY 3092, 3098 (2005); Thomas V. Perneger et al., *Race and End-Stage Renal Disease: Socioeconomic Status and Access to Health Care as Mediating Factors*, 155 ARCHIVES INTERNAL MED. 1201, 1201–03 (1995).

39. Hippen, *supra* note 35.

40. Jack J. Curtis, *Ageism and Kidney Transplantation*, 6 AM. J. TRANSPLANTATION 1264 (2006); Gabriel M. Danovitch, *A Kidney for All Ages*, 6 AM. J. TRANSPLANTATION 1264 (2006).

the confirmed superiority of transplantation compared to dialysis sets the stage for an updated version of the classic lifeboat quandary, “who shall live?”⁴¹—a question confronting the first dialysis center, which opened in Seattle in 1962, a time when extremely limited access to dialysis resembled the organ shortage of today.⁴²

III. History of Dialysis and Organ Rationing

A. Dialysis 1960 to 1962: The Seattle Artificial Kidney Center and the Evolution of Dialysis

Chronic dialysis became a clinical reality in 1960, but for fifteen years prior to that, the dialysis machine—or, as it was then called, the artificial kidney—was used only for short-term treatment in patients suffering reversible renal failure.⁴³ The first successful dialysis treatment took place in Holland in September 1945, just months after the Nazi occupation had ended.⁴⁴ A Dutch physician named Willem Kolff had worked heroically through the war years to develop the artificial kidney.⁴⁵ His dialysis procedure required insertion of two large-bore glass tubes called “cannulae,” one into an artery (from which blood flowed under natural pressure to the artificial kidney where it was cleansed) and the other into a vein to receive purified blood returning to the body.⁴⁶ The vessels collapsed and clotted each time these glass cannulae were removed, making the vessels impossible to use again.⁴⁷ It took only about a month before all of the body’s vascular access

TATION 1267 (2006); Gabriel C. Oniscu et al., *How Old Is Old for Transplantation?*, 4 AM. J. TRANSPLANTATION 2067 (2004).

41. See generally Garrett Hardin, *Living on a Lifeboat*, 24 BIOSCIENCE 561–68 (1974).

42. See Kausz et al., *supra* note 38 (discussing the confirmed superiority of transplantation compared to dialysis); Shana Alexander, *Medical Miracle and a Moral Burden of a Small Committee: They Decide Who Lives, Who Dies*, LIFE, Nov. 9, 1962, at 102.

43. Christopher R. Blagg et al., *The History and Rationale of Daily and Nightly Hemodialysis*, 145 CONTRIBUTIONS TO NEPHROLOGY 1, 2 (2004), available at <http://content.karger.com/ProdukteDB/produkte.asp?Doi=81666>.

44. Lawrence K. Altman, *2 Doctors Cited for Work Developing Artificial Kidney*, N.Y. TIMES, Sept. 22, 2002, § 1, at 36.

45. *Id.*

46. See Blagg et al., *supra* note 43, at 2.

47. *Id.*

points were exhausted.⁴⁸ Unless the patient took a turn for the better within that window of time, the patient would die.⁴⁹

It was heartbreaking for physicians and loved ones to see patients' Lazarus-like recoveries from the effects of renal failure, only to lapse back into a uremic coma and die once their arteries and veins had been used up by the dialysis procedure. The artificial kidney would remain merely a temporizing measure in the care of patients with irreversible kidney failure until the advent of more reliable access to veins and arteries. One night in 1960, the problem was solved by Belding Scribner, a nephrologist at the University of Washington.⁵⁰ According to legend, Scribner awoke in the middle of the night and drew a plan for a U-shaped shunt that could connect indwelling cannulae in an artery and vein, thus allowing blood to circulate continuously between the vessels, keeping them open.⁵¹ Equally crucial, the device used the new material, Teflon tubing, whose nonstick surface drastically reduced clotting and thereby established the long-lasting access that made sustained dialysis possible.⁵²

On March 9, 1960, Dr. Scribner implanted the shunt in the arm of Clyde Shields, a thirty-nine-year old Boeing machinist, and the consequences were momentous.⁵³ With the first surge of blood through the shunt, it became possible for ESRD to transform from an inevitably fatal disease into a chronic condition. "Suddenly, we took something that was 100 percent fatal and overnight turned it into 90 percent survival," Scribner said.⁵⁴ This dramatic advance would go on to make dialysis a routine therapy, but before it assumed that legacy, another challenge loomed: although dialysis could be tailored to a handful of individuals, there was still no way to provide it on a large scale to the thousands of patients who might benefit from this still experimental procedure. Indeed, soon after the successful dialysis of Mr. Shields,

48. *See generally id.* (noting that vessel collapse "limited the number of treatments that could be carried out").

49. *See id.*

50. Joseph G. Herman, *Dialysis Pioneer Belding H. Scribner Dies at Age 82*, KIDNEY NEWS, Fall 2003, at 1-2, available at <http://www.kidney.bc.ca/do/newsletter/documents/KFNewsletterFall2003.pdf>.

51. *Id.* at 2.

52. *Id.* at 2-3.

53. *Id.* at 3.

54. *Id.*

the University of Washington Hospital was inundated with requests from physicians and patients from across the country.⁵⁵

B. Rationing by Committee

Famously charismatic, Dr. Scribner managed to secure private funding for three years to design an experimental program.⁵⁶ When the Seattle Artificial Kidney Center opened in January of 1962, about sixty patients in the Seattle area were known to be in need of dialysis, though only nine patient slots were available.⁵⁷ Who among the dying should get them? Dr. Scribner argued that the job of choosing among medically eligible candidates should not be reserved for clinicians; rather, the authority and the burden of such decisions ought to be shouldered by society.⁵⁸

This view became the impetus for the establishment of a lay committee, formally known as the Admissions and Policy Committee of the Seattle Artificial Kidney Center at Swedish Hospital.⁵⁹ The committee was composed of seven lay people—a lawyer, a minister, a housewife, a state government official, a labor leader, a banker, and a surgeon—and was among the earliest, if not the first, instance of physicians bringing nonprofessionals into the realm of clinical decision making.⁶⁰ The lay committee members were unpaid volunteers, and they insisted on remaining anonymous so that the medical staff, the public, and especially the applicant-patients whose written information they reviewed would never know their identities.⁶¹

Before reaching the lay committee, however, prospective donees had to clear several hurdles. First, a panel of physicians would winnow applicants according to likelihood of medical benefit.⁶² This meant no one over the age of forty-five and no one with conditions such as preexisting diabetes or high blood pressure that might com-

55. Jeanne Lenzer, *Belding Scribner: The Inventor of Shunt Dialysis*, 327 BRIT. MED. J. 167, 167 (2003), available at <http://www.bmj.com/cgi/reprint/327/7407/167>.

56. Nw. Kidney Ctrs., History of Northwest Kidney Centers, <http://www.nwkidney.org/about/history/index.html> (last visited Feb. 12, 2007).

57. *Id.*

58. Lenzer, *supra* note 55.

59. Herman, *supra* note 50, at 4.

60. *See id.*

61. Alexander, *supra* note 42, at 106; *see also* RENÉE C. FOX & JUDITH P. SWAZEY, *THE COURAGE TO FAIL: A SOCIAL VIEW OF ORGAN TRANSPLANTS AND DIALYSIS* 245 (Univ. of Chi. Press 1974).

62. FOX & SWAZEY, *supra* note 61.

plicate his or her care would be considered for treatment.⁶³ Second, a psychologist would conduct a home visit to interview the patient's family and friends to determine whether the patient was mentally fit and sufficiently disciplined to comply with the demands of dialysis—the regular, never-ending series of treatments, the austere diet, and the need to keep the shunt clean and protected.⁶⁴ The patient had to be cooperative with staff and tolerant of dialysis complications, such as clotting of the shunt, infections, and the stress of being intimately dependent upon a machine.⁶⁵ Next, a financial committee would determine a patient's ability to pay the \$10,000 yearly cost.⁶⁶ Fortunately, few patients were denied care on these grounds, as the financial aid staff of the Seattle Artificial Kidney Center was usually able to cobble together funding from government, private, and other sources.⁶⁷ Depending upon patient flow through the center, the committee had to consider several patients at a time or only one.⁶⁸ In the latter instance, the sole applicant was not guaranteed a slot.⁶⁹ In its first thirteen months, the committee considered thirty candidates; of the seventeen that were medically suitable, ten were chosen for treatment and seven died.⁷⁰

The members of the lay committee took their Solomonic charge seriously. "As human beings ourselves," the lawyer had said, "we rejected the idea instinctively, of classifying other human beings in pigeonholes, but we realized we had to narrow the field somehow."⁷¹ Years later, Reverend John B. Darrah, the head of the committee, wrote that "[d]ominant in our decisions seemed to be the search for the unknown and uncertain factors: who and how many would be

63. *Id.*

64. *Id.* at 250.

65. Belding Scribner et al., *Some Therapeutic Approaches to Chronic Renal Insufficiency*, 16 ANN. REV. MED. 285, 291 (1965).

66. Richard A. Rettig, *The Federal Government and Social Planning for End-Stage Renal Disease: Past, Present, and Future*, 2 SEMINARS NEPHROLOGY 111, 117 (1982).

67. E-mail from Christopher Blagg, Professor Emeritus of Med., Univ. of Wash., to Sally L. Satel, Resident Scholar, Am. Enter. Inst. (Oct. 2, 2006) (on file with author).

68. Rettig, *supra* note 66.

69. E-mail from Christopher Blagg, Professor Emeritus of Med., Univ. of Wash., to Sally L. Satel, Resident Scholar, Am. Enter. Inst. (Jan. 12, 2007, 12:50 EST) (on file with author).

70. Rettig, *supra* note 66.

71. Alexander, *supra* note 42, at 115.

most affected by the demise of the patient?"⁷² Determining who and how many would be most affected required consideration of many factors, among them the applicant's income, gender, marital status, net worth, nature of occupation, extent of education, church attendance, number of dependents (more dependents conferred a better chance of being chosen), and potential for rehabilitation if disabled by kidney disease.⁷³ The committee tried to determine whether a precious artificial kidney should save the person who would contribute the most to society or the one whose death would impose the greatest burden on society in the form of dependent children.⁷⁴

Within five months of its founding, the lay committee of the Seattle Artificial Kidney Center was thrust into the public eye. In late April 1962, Dr. Scribner and colleagues described the Seattle program at the annual meeting of the American Society for Clinical Investigation, and a week later the *New York Times* ran a front page story, "Panel Holds Life-or-Death Vote in Allocating Artificial Kidney."⁷⁵ In November 1962, *Life*, the sixties' most influential popular weekly magazine, ran a story about the committee by journalist Shana Alexander⁷⁶ and drew national attention to what was happening in Seattle.⁷⁷ Alexander dubbed it the "Life or Death Committee," and the accompanying photo spread depicted the committee members, in silhouette, as if sitting in harsh judgment.⁷⁸ Thirty years later, she gave a speech about her experience called "Thirty Years Ago."⁷⁹

Belding Scribner said that he was accused of helping create the lay committee "simply for publicity" to call attention to the dialysis

72. John B. Darrah, *The Committee*, 33 TRANSACTIONS AM. SOC'Y ARTIFICIAL INTERNAL ORGANS 791 (1987).

73. FOX & SWAZEY, *supra* note 61, at 245-46.

74. GERALD LEACH, *THE BIOCRATS (ETHICS AND THE NEW MEDICINE)* 223 (1970).

75. Harold M. Schmeck, Jr., *Panel Holds Life-Or-Death Vote in Allotting of Artificial Kidney*, N.Y. TIMES, May 6, 1962, at 1.

76. Alexander, *supra* note 42, at 106.

77. FOX & SWAZEY, *supra* note 61, at 241 ("In retrospect, of course, we were terribly naive. We did not realize even then the full impact that the existence of this committee would have on the world. [We] simply could not understand why everyone was much more interested in the existence of [the lay committee] than in the fact that in two years we had taken a disease, end-stage kidney disease, and converted it from a 100% fatal prognosis to 95% two year survival.").

78. Alexander, *supra* note 42, at 106.

79. Shana Alexander, *Thirty Years Ago*, 23 HASTINGS CENTER REP. 55, 55 (1993).

shortage, a charge he vehemently denied.⁸⁰ Nonetheless, media attention swirled. In August 1963, a *Wall Street Journal* story headlined "Medical Irony: Kidney Machines Save 'Doomed' Patients' Lives but Raise Ethical Issue" noted that Dr. Scribner's breakthrough was "now giving way to anxious soul-searching over costs . . . forcing doctors to make difficult life-and-death decisions."⁸¹ Two years later, in 1965, Edwin Newman narrated an NBC documentary about the Seattle program called "Who Shall Live?" which focused on the lay committee.⁸²

C. Rationing and Its Discontents

Contemporary accounts of the Seattle program tended to merely describe the moral dilemma facing physicians, but most commentators were more circumspect—and generally disapproving—in their assessments of Seattle's mode of rationing care. "Ad hoc decision making opens the door wide to the rule of personal bias," observed ethicist John Kilner.⁸³ "Overall, the chosen will resemble the choosers."⁸⁴ Many critics considered selection of dialysis recipients based upon determinations of human worth to be an affront to the ideal of equality; the moral claim of each patient to treatment was equivalent, the critics argued.⁸⁵ One essay in the *UCLA Law Review* bitingly observed that "[t]he Pacific Northwest is no place for a Henry David Thoreau with bad kidneys," thereby chiding the committee for ruling out creative nonconformists.⁸⁶

In their book *Tragic Choices*, Guido Calabresi and Philip Bobbitt delineated these intractable conflicts and found that most wrenching for citizens and policymakers are choices between fundamental values

80. Belding H. Scribner, *Letters and Comments: Moral Problems of Artificial and Transplanted Organs*, 61 *ANNALS INTERNAL MED.* 355, 357 (1964).

81. Herrert Lawson, *Kidney Machines Save "Doomed" Patients' Lives but Raise Ethical Issues*, *WALL ST. J.*, Aug. 22, 1963, at 1.

82. Deborah L. Illman, *Pioneers in Kidney Dialysis: From the Scribner Shunt and the Mini-II to the "One Button Machine,"* in *PATHBREAKERS* (Alvin L. Kwiram ed., 1996), available at <http://www.washington.edu/research/pathbreakers/1960c.html>.

83. JOHN F. KILNER, *WHO LIVES? WHO DIES?* 16 (1990).

84. *Id.* at 17.

85. RENAL PHYSICIANS ASS'N & AM. SOC'Y OF NEPHROLOGY, *CLINICAL PRACTICE GUIDELINE ON SHARED DECISION-MAKING IN THE APPROPRIATE INITIATION OF AND WITHDRAWAL FROM DIALYSIS* (1999), available at <http://www.kidneyeol.org/M-RPA%20and%20ASN%20Clinical%20Practice%20Guidelines.doc>.

86. David Sanders & Jess Dukeminier, Jr., *Medical Advances and Legal Lag: Hemodialysis and Kidney Transplantation*, 15 *UCLA L. REV.* 357, 378 (1968).

and choices between a fundamental value and scarcity.⁸⁷ To mitigate public anxiety, Calabresi and Bobbitt claim, decision making may be postponed or, if carried out, the very fact of its execution may be denied outright, with the unfortunate but foreseen outcome subsequently attributed to fate.⁸⁸ They point to the evolution of dialysis selection as illustrative.⁸⁹

When the Seattle lay committee examined social factors in such an explicit fashion, the result generated intolerable anxiety among physicians, legal and ethics scholars, policymakers, and the media. To avert heated controversy, the subsequent generation of dialysis clinics were careful not to make determinations based on such factors as income, church attendance, or the presence of a traditional family structure.⁹⁰ Instead, patient selection proceeded according to an estimate by clinicians of the probability of medical success.⁹¹ The unstated premise of what initially appeared to be a more objective approach was that there was a close correlation between the likelihood of a good medical outcome and conventionally positive social traits. In the words of Calabresi and Bobbitt, "efficiency-guided distributions correlated with wealth differences [among patients]."⁹²

Allocation of dialysis was among the first tragic choices to arise in the modern era of medical innovation. "It was a very important moment," according to Albert R. Jonsen, professor of ethics in medicine at the University of Washington and author of *The Birth of Bioethics*.⁹³ "[I]t aroused the first national discussion about the ethics of applying new medical technologies."⁹⁴ The Seattle experience and its aftermath brought into uncomfortable focus the tension between limited resources and seemingly limitless need. Obvious solutions were not forthcoming, and the dawn of the civil rights movement and student uprisings in the early 1960s eroded the authority to make and en-

87. GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* (1978).

88. *Id.* at 21–22.

89. *Id.* at 22–25.

90. *Id.* at 188–89.

91. *Id.* at 189.

92. *Id.* at 24.

93. Will Morton, *Al Jonsen Produces Sourcebook and History of Bioethics*, UNIV. WEEK, July 23, 1998, available at http://depts.washington.edu/~uweek/archives/1998.07.JUL_23/_article14.html; see also ALBERT R. JONSEN, *THE BIRTH OF BIOETHICS* (1998).

94. *Id.*

force such decisions.⁹⁵ When a treatment is scarce, should society spend exorbitant amounts of money to rescue relatively few people in order to avoid rationing? Would the funds to save a few from renal failure be better directed toward other illnesses that afflict many? If we are to ration dialysis, and thus choose who its beneficiaries will be, how, precisely, do we make such a choice?⁹⁶

The questions persisted: should decision makers employ a first-come, first-served arrangement, a committee selection (and which criteria?), or a market approach based on those who can pay? Random allocation was also considered, though many physicians felt that blind assignment amounted to an abdication of the moral responsibility to choose and a refusal to face the brutal necessity of choice.⁹⁷ Another possibility was to opt out completely and refuse to make the resource available to anyone if it could not be guaranteed to all; at least two hospitals were reported to have done this.⁹⁸

For the first twelve years of dialysis, from inception in 1960 until 1972, when broad federal funding for dialysis patients was instituted, the tragic choice was uneasily resolved in favor of rationing.⁹⁹ The country's veterans were the fortunate exception. In 1963, the Veterans Administration opened thirty dialysis centers to serve all eligible veterans.¹⁰⁰ Elsewhere, there were not enough artificial kidneys, facilities in which to house them, or medical experts to operate and monitor them.¹⁰¹ To support care, dialysis centers relied on a patchwork of funding sources, such as the U.S. Public Health Service, the National Institutes of Health, state kidney programs, and community fund-raising drives.¹⁰² Private insurance rarely covered dialysis care.¹⁰³ In

95. ROBERT M. VEATCH, *DISRUPTED DIALOGUE* 181–82 (2005) (discussing how the social and political climate of the 1960s led to more lay people insisting on a larger role in moral decision making).

96. JONSEN, *supra* note 93, at 211–17 (discussing the factors that the Seattle Artificial Kidney Center considered when selecting patients); Illman, *supra* note 82.

97. ALBERT R. JONSEN, *BIOETHICS BEYOND THE HEADLINES: WHO LIVES? WHO DIES? WHO DECIDES?* 145–46 (2005).

98. KILNER, *supra* note 83, at 15; *see also* CALABRESI & BOBBITT, *supra* note 87, at 188 n.114.

99. Richard A. Rettig, *Historical Perspective*, in *ETHICS AND THE KIDNEY* 6–7 (Norman G. Levinsky ed., 2001).

100. *Id.* at 6.

101. *Id.* at 6–7.

102. E-mail from Christopher Blagg, Professor Emeritus of Med., Univ. of Wash., to Sally L. Satel, Resident Scholar, Am. Enter. Inst. (Dec. 17, 2006) (on file with author).

1965, two major health entitlements were established: Medicaid for the indigent, and Medicare for those older than sixty-five years of age.¹⁰⁴ Theoretically, these two programs could have paid for patients on dialysis, but it is unlikely that their constituents would have been eligible for the treatment in the first place. After all, most Medicaid patients would have been medically or psychologically unsuitable to be chosen for dialysis, and Medicare patients would have simply been rejected by dialysis programs on the basis of age.¹⁰⁵

Constraints on funding for dialysis made continued rationing inevitable. However, what did change in the wake of the Seattle "Life or Death Committee" was that patient selection committees now comprised physicians and generally excluded lay people, while being less explicit about making judgments regarding human worth. "Physicians learned from Seattle to avoid the 'costs' of being highly visible in decision-making about who received treatment," according to Richard Rettig, a political scientist who meticulously detailed the social and legislative history of dialysis policy.¹⁰⁶ Most medical facilities still took candidates' personal and circumstantial details into consideration, but they subsumed these social criteria into clinical judgments. This reflected the simple fact that the features believed to make a person a good medical risk for dialysis were less common among the economically disadvantaged. Allocation premised upon the utilitarian principle of maximizing outcome by asking which patients would get the most productive years out of dialysis naturally favored candidates perceived as more conscientious, better educated, and more likely to be beneficiaries of the emotional and instrumental support that come from stable families. In contrast, poorer people were understood to lead more chaotic lives, making compliance with dialysis schedules and dietary restrictions less certain, and they often suffered additional medical conditions assumed to undercut the effectiveness of dialysis.¹⁰⁷ Choosing who gets treatment based on a utilitarian definition of medical suitability meant that the socially disenfranchised were almost guaranteed to lose.

103. Christopher R. Blagg, *The History of Home Hemodialysis: A View from Seattle*, 1 HOME HEMODIAL INT'L 1 (1997), available at <http://www.multi-med.com/homehemo/blaggarticle/main.html>.

104. Social Security Amendments of 1965, Pub. L. No. 89-97 (1965).

105. Alvin H. Moss, *Dialysis Kidney*, in *ENCYCLOPEDIA OF BIOETHICS* 649 (Stephen G. Post ed., 2004) (1978).

106. Rettig, *supra* note 66, at 126.

107. *See id.* at 127-30.

How did a post-Seattle committee actually work? According to a 1969 survey of dialysis facilities, committees judged a patient's willingness to cooperate with the treatment regimen as the single most important factor.¹⁰⁸ Good prospects for job rehabilitation were also a high priority.¹⁰⁹ About a quarter of the committees administered IQ, personality, and vocational tests to prospective dialysis patients.¹¹⁰ Only a few centers disqualified candidates on principle if they had criminal records, poor employment histories, or financial difficulties, though the latter group's chances of being chosen were not good, as patients had to be able to pay for their care.¹¹¹

The Los Angeles County dialysis center, for example, selected a pool of medically, psychologically, and socially optimal candidates, and then chose among them by lottery.¹¹² The Peter Bent Brigham dialysis program in Boston considered three factors: likelihood of return to useful societal role, absence of any other disabling condition, and ability to cooperate with care.¹¹³ The Detroit Receiving Hospital assessed patients for medical suitability on a first-come, first-served basis.¹¹⁴ The Cleveland Clinic was less restrictive, taking all patients on a first-come, first-served basis but then culling patients after starting dialysis if they proved to be unwilling or unable to cooperate.¹¹⁵

D. The End of Rationing . . . for Dialysis

Throughout the 1960s, physicians advocated federal funding for dialysis.¹¹⁶ Reliable demographic surveys of patients on dialysis during this period are scarce but there is no doubt that thousands died annually from renal failure—10,000 is a much-cited estimate—because

108. See FOX & SWAZEY, *supra* note 61, at 244.

109. KILNER, *supra* note 83, at 28 (stating that 76% of dialysis centers studied in the late 1960s and early 1970s used job rehabilitation potential as a factor).

110. FOX & SWAZEY, *supra* note 61, at 244.

111. *Id.*

112. Sanders & Dukeminier, Jr., *supra* note 86, at 372 n.45.

113. Eugene Schupack & John P. Merrill, *Experience with Long-Term Intermittent Hemodialysis*, 62 ANNALS INTERNAL MED. 509 (1965).

114. Sanders & Dukeminier, Jr., *supra* note 86, at 381 n.79.

115. Nancy D. Barber et al., *Pathologic Anatomy of 13 Patients After Prolonged Periodic Hemodialyses*, 9 TRANSACTIONS AM. SOC'Y ARTIFICIAL INTERNAL ORGANS 21, 21 (1963) ("Renal insufficiency severe enough to preclude life without chronic dialysis was the sole criterion for admission to the program when space was available.").

116. Rettig, *supra* note 99, at 8–10.

they could not get access to dialysis.¹¹⁷ Concerns about the cost and efficacy of dialysis kept Congress from funding patient care per se, but Congress did appropriate monies for research on kidney disease, building and maintaining dialysis facilities, and training nephrologists.¹¹⁸ It was not until 1972, however, that Congress passed an amendment to the Social Security Amendments Act, formally known as Section 2991, mandating that Medicare pay for treatment of ESRD.¹¹⁹ Senator Vance Hartke of Indiana, who introduced the amendment,¹²⁰ said of patients denied dialysis that “[theirs] will be needless deaths—deaths which should shock our conscience and shame our sensibilities.”¹²¹

Several trends had converged to produce the new law. Starting in the mid 1960s, momentum was building on several fronts: the populist sympathies of key congressional representatives such as Wilbur Mills (D-Ark.) and Russell Long (D-La.); the lobbying efforts of the National Kidney Disease Foundation and the American Medical Association; the establishment of dialysis as a proven life-saving technology; and the drama of so-called identified lives—specific patient-constituents who personally appealed to their politicians to save them—and stories in the press about the tragic choices that needed to be made.¹²² That a man could die within a week if he could no longer afford his life-saving machine was an emotionally compelling scenario, one made even more arresting by the fact that this man lived in

117. In 1965, for example, Scribner estimated that seventy-five to 100 people nationwide were being treated with dialysis. *Who Shall Live?* (NBC television broadcast Nov. 28, 1965). By 1967, there were perhaps 100 dialysis centers serving about 1000 patients. See Rettig, *supra* note 99, at 8. Though dialysis was available in almost every state by 1971, one commonly cited estimate was that only about 5000 people were receiving it. Peter A. Lundin & Fritz K. Port, *Adequacy of Treatment for End-Stage Renal Disease in the United States*, 41 *ADVANCES INTERNAL MED.* 323, 328 (1996). By 1972, there were almost 6000 patients receiving dialysis. FOX & SWAZEY, *supra* note 61, at 363. Estimates of deaths due to limited access to dialysis ranged from between 7000 and 10,000 annually. See KILNER, *supra* note 83, at 4 (stating that only 800 people received hemodialysis by the mid-1960s, though there were at least 10,000 suitable candidates).

118. See RICHARD A. RETTIG & ELLEN L. MARKS, *HEALTH CARE FINANCING GRANTS AND CONTRACT REPORTS: IMPLEMENTING THE END-STAGE RENAL DISEASE PROGRAM OF MEDICARE* 25–27 (1981).

119. Social Security Amendments of 1972, Pub. L. No. 92-603, 86 Stat. 1329 (codified as amended in scattered sections of 42 U.S.C.).

120. RETTIG & MARKS, *supra* note 118, at 29.

121. 118 CONG. REC. S33003 (daily ed. Sept. 30, 1972) (statement of Sen. Hartke).

122. Richard Rettig, *The Policy Debate on Patient Care Financing for Victims of End Stage Renal Disease*, 40 *LAW & CONTEMP. PROBS.* 196, 219–20 (1976).

an affluent country.¹²³ As Senator Henry Jackson of Washington State said, "I think it is a great tragedy that in a nation as affluent as ours, that we have to consciously make a decision all over America as to the people who live and the people who will die. I think we can do better than that . . ."¹²⁴ Subsequently, new technology was made available to all, and the need to ration disappeared.

The Medicare ESRD program is the only federal disease-specific entitlement ever enacted in the United States.¹²⁵ It covers dialysis and transplantation (which is more cost-effective than dialysis) regardless of age, income, insurance coverage, or disability status, as long as the patient satisfies the work-credit requirement for Social Security.¹²⁶ Like so many public entitlements, however, its consequences were only superficially understood at the time of enactment. Within months of the entitlement's creation, the *New York Times* ran an editorial headlined "Medicarelessness," chiding Congress for not realizing what it had gotten itself into.¹²⁷ Indeed the program's scope and expense enlarged dramatically and unexpectedly soon after its implementation.

The number of patients escalated quickly. Although early estimates predicted as many as 10,000 new dialysis patients each year and that within a few years the patient pool would level out at about 35,000,¹²⁸ the number of patients added each year turned out to be much higher: 14,000 were added in 1978, 32,000 were added in 1986, and 75,000 were added in 1998.¹²⁹ Recent years witnessed the same persistent growth, with 104,364 patients enrolled in 2004.¹³⁰

Expenditures ballooned as well. In 1974, the program's first year of implementation, expenditures were \$229 million, and expectations were that costs would level out at \$250 million.¹³¹ However, expenditures reached \$1.4 billion in 1980 and \$3 billion in 1987.¹³² By 1998, the

123. *Id.* at 224.

124. 118 CONG. REC. S33007 (daily ed. Sept. 30, 1972) (statement of Sen. Jackson).

125. RETTIG & MARKS, *supra* note 118, at 5.

126. 42 U.S.C. § 426-1(1)(A) (2006).

127. *Medicarelessness*, N.Y. TIMES, Jan. 14, 1973, at 16.

128. Paul W. Eggers, *Medicare's End Stage Renal Disease Program*, 22 HEALTH CARE FINANCING REV. 55, 57 (2000).

129. *Id.*

130. 2006 ANNUAL DATA REPORT, *supra* note 5, at 69 tbl.2.1.

131. See Eggers, *supra* note 128, at 58; Rettig, *supra* note 66, at 111.

132. Paul W. Eggers, *A Quarter Century of Medicare Expenditures for ESRD*, 20 SEMINARS NEPHROLOGY 516, 519 tbl.2 (2000).

cost had ballooned to \$12.3 billion.¹³³ In part, the large influx of patients reflected an incomplete understanding of the extent of ESRD—for example, the fact that the prevalence of the affliction among blacks is nearly four times higher than among whites.¹³⁴

But the explosion in costs was primarily due to other critical factors, namely the characteristics of patients previously excluded from dialysis. During the era of rationing, dialysis clinics served almost exclusively young and middle-aged patients who were otherwise relatively healthy and emotionally mature.¹³⁵ These patients were conscientious, enjoyed good social support, and were more likely to be employed than the patients admitted after 1972.¹³⁶ By comparison, the post-1972 clinics admitted many patients who were prone to expensive medical complications because they did not follow the diet, were not vigilant about shunt maintenance, or skipped dialysis sessions.¹³⁷ They were also older and sicker, thereby making them more vulnerable to dialysis-related medical conditions, especially cardiovascular disease.¹³⁸ Finally, the expansion of the federal entitlement that covers renal failure is due to improvements in dialysis itself. As nephrologists and dialysis centers became better at treating patients, referring physicians sent them increasingly fragile patients for care. In the last fifteen years, some nephrologists and bioethicists have charged that

133. *Id.*

134. John K. Iglehart, *The End Stage Renal Disease Program*, 328 NEW ENG. J. MED. 366 (1993).

135. See LEACH, *supra* note 74, at 226 (recounting one nephrologist's statement that these patients had to have "emotional stoicism, self control and average intelligence").

136. See Roger W. Evans et al., *A Social and Demographic Profile of Hemodialysis Patients in the United States*, 245 JAMA 487, 487-89 (1981) (comparing pre-1972 and post-1972 characteristics of the hemodialysis patient population, and noting that until 1973, "social class considerations and social worth often were more important than other more equitable and less controversial criteria").

137. The ESRD program had been accepting patients for only four years in 1978, by which time the demographic of the dialysis population had changed markedly compared with the year 1967. Evans et al., *supra* note 136, at 488-89. Representation of white patients declined from 90% to 64%, while black patients grew from 7% to 35%. *Id.* The dialysis population also aged. In 1967, 7% of patients were older than the age of fifty-five, but by 1978, 46% were older than fifty-five. *Id.* The percentage of employed patients dropped from 42% to 18%. *Id.* Intriguingly, the proportion of men had dropped from three-quarters in 1967 to one-half by 1978. *Id.* In 1978, 10% of dialysis patients were diabetic, but by 1998, the proportion grew to 45%. Eggers, *supra* note 128; see also Eli A. Friedman, *Hyperglycemic (and Diabetic) Glomerulopathy*, 15 KIDNEY 1 (1982).

138. See Robert A. Gutman et al., *Physical Activity and Employment Status of Patients on Maintenance Dialysis*, 304 NEW ENG. J. MED. 309, 312 (1981) (noting that 44% of these patients were too sick to work).

dialysis availability has become too lenient, particularly when it is initiated in moribund patients or when irreversibly ill or severely demented patients are allowed to remain on it.¹³⁹

IV. Organ Donation Today

A. Scarce Organs and the Elderly

It is ironic that the elderly, a group specifically excluded from dialysis during the early rationing years, quickly became the fastest growing segment of the dialysis population and, later, of the transplant waiting list.¹⁴⁰ At the end of 2006, patients ages sixty-five and over represented 16% of the waiting-list population, a modest proportion compared with their nearly one-in-two ratio within the dialysis population.¹⁴¹ However, their numbers on the waiting list have been increasing from year to year at a significantly higher rate compared to growth in all other age groups.¹⁴²

There are no UNOS-imposed restrictions on who may receive a cadaver kidney, assuming the patient is medically eligible.¹⁴³ However, individual transplant centers have discretion to set their own policies regarding waiting-list enrollment and whether to proceed with transplants when organs become available.¹⁴⁴ A recent article in

139. Alvin H. Moss, *A New Clinical Practice Guideline on Initiation and Withdrawal of Dialysis That Makes Explicit the Role of Palliative Medicine*, 3 J. PALLIATIVE MED. 253, 253–54 (2000); Anne M. Murray et al., *Cognitive Impairment in Hemodialysis Patients Is Common*, 67 NEUROLOGY 216, 219–20 (2006); Barron H. Lerner, *Choosing a 'God Squad' When the Mind Has Faded*, N.Y. TIMES, Aug. 29, 2006, at F5.

140. Danovitch, *supra* note 40, at 1268.

141. *Id.*

142. *Id.* at 1267–68.

143. The criteria for being medically eligible for organ allocation include: (1) the likelihood of benefit to the patient; (2) the impact of treatment in improving the quality of the patient's life; (3) the duration of benefits; and (4) in some cases, the amount of resources required for successful treatment. See AM. MED. ASS'N, POLICY NO. H-370.982, ETHICAL CONSIDERATIONS IN THE ALLOCATION OF ORGANS AND OTHER SCARCE MEDICAL RESOURCES AMONG PATIENTS, available at http://www.ama-assn.org/apps/pf_new/pf_online (search "H-370.982") (last visited Apr. 8, 2007).

144. Thus, by virtue of being listed in the first place, irrespective of age, a patient has been deemed a reasonable candidate. Accordingly, transplantation rates approximately reflect list membership. As of February 2007, individuals ages sixty-five and older represented about 16% of the kidney waiting list, while those between the ages of thirty-five and forty-nine represented 30%, and those between the ages of fifty and sixty-five represented 42%. Organ Procurement & Transplantation Network, Organ by Age, <http://www.optn.org/data> (select "National Data" on left; then select "Waiting List" category; then select "Organ by Age" report) (last visited Feb. 12, 2007). At the same time, individuals ages sixty-five and

the *Los Angeles Times* is illustrative.¹⁴⁵ Clois Guthrie was an eighty-five-year-old retired osteopathic surgeon from North Denver who had been on dialysis for three years awaiting a kidney.¹⁴⁶ When one became available, the physicians at the transplant center where Guthrie was to undergo surgery confronted an anguished decision: should they give him the next available kidney—which happened to be from a thirty-year-old man killed in a motorcycle accident—or divert it to a younger person who would derive more years from the organ?¹⁴⁷ They finally decided to proceed with his surgery, but there was a technical glitch at the last minute, and the operation did not take place.¹⁴⁸

Dr. Guthrie's case was a watershed for the transplant surgeons and staff at the Denver hospital. It spurred the team to reexamine its policy on age.¹⁴⁹ After much deliberation, the team decided that patients between the ages of seventy and seventy-nine would be eligible for two kinds of transplanted organs: subpar organs from deceased donors, or organs donated by the patient's friend or relative.¹⁵⁰ No patient over age seventy-nine would be accepted for transplantation of any kind.¹⁵¹

The growing demand for transplantable organs has stimulated efforts on multiple fronts to increase the supply. Most recently, the Organ Donor Collaborative Network identified "best practice" approaches to soliciting and successfully procuring organs from deceased donors and reexamining the practices and rationale for discarding organs believed to be suboptimal for transplantation.¹⁵² Consequently, more organs from so-called extended-criteria donors, which include donors older than fifty-five, or with comorbid condi-

over represented 13% of those who received a kidney transplant, while those between the ages of thirty-five and forty-nine received 28% of kidney transplants and the fifty-to-sixty-five age group received 38% of the transplants. Organ Procurement & Transplantation Network, Transplants in the U.S. by Recipient Age, <http://www.optn.org/data> (select "National Data" on left; then select "Transplant" category; then select "Transplants by Recipient Age" report; then specify "Kidney" as the organ) (last visited Feb. 12, 2007).

145. Alan Zarembo, *How Old Is Too Old for a Transplant?*, L.A. TIMES, Nov. 5, 2006, at A1.

146. *Id.* at A2.

147. *Id.* at A1-3.

148. *Id.* at A3.

149. *Id.* at A5.

150. *Id.*

151. *Id.*

152. *Id.* at A1.

tions such as hypertension and diabetes, have become an important new source for transplantable organs.¹⁵³

Additionally, potential donors suffering cardiopulmonary death prior to brain death have increasingly garnered more attention following a report by the Institute of Medicine exploring the practical feasibility and ethical permissibility of soliciting and procuring organs under these circumstances.¹⁵⁴ Although the majority of deceased donors are declared dead by brain-death criteria, organs have been successfully transplanted from non-brain-dead donors whose critical illnesses warranted the withdrawal of aggressive life-sustaining measures. Preliminary data suggests that the outcomes of such transplants are comparable to outcomes of standard-criteria kidney transplants.¹⁵⁵

Along with efforts to increase the supply, advances in the understanding of transplant immunology can offer new opportunities. These advances apply to patients who possess an uncommon blood type, as well as those who have high levels of tissue antibodies in their blood, also called "highly sensitized" recipients, and who are therefore notoriously difficult to match with a donor kidney.¹⁵⁶ For example, knowledge that blood group A consists of two subgroups (A1 and A2) has led to the observation that, under certain circumstances, a kidney from a donor of blood type A2 can successfully be transplanted into a recipient of blood type O without additional risk of rejection.¹⁵⁷ More sensitive methods of identifying non-blood-group antibodies in highly sensitized recipients has led to the possibility of offering more organs to candidates who were initially considered ineligible for transplantation due to almost insurmountable immunologic barriers.¹⁵⁸

153. INST. OF MED., ORGAN DONATION: OPPORTUNITIES FOR ACTION 161 (James F. Childress & Catharyn T. Liverman eds., 2006).

154. *Id.*

155. James L. Bernat et al., *Report of a National Conference on Donation after Cardiac Death*, 6 AM. J. TRANSPLANTATION 281, 285 tbl.5 (2006).

156. See generally Paul W. Nelson et al., *Increased Access to Transplantation for Blood Group B Cadaveric Waiting List Candidates by Using A2 Kidneys: Time for a New National System?*, 2 AM. J. TRANSPLANTATION 94 (2002).

157. *Id.* at 96.

158. See, e.g., Robert A. Bray et al., *Transplanting the Highly Sensitized Patient: The Emory Algorithm*, 6 AM. J. TRANSPLANTATION 2307 (2006); Benjamin Hippen, Editorial, *The Sensitized Recipient: What Is to Be Done?*, 6 AM. J. TRANSPLANTATION 2230 (2006).

B. New Donation Practices

The fastest growing source of transplantable organs is living donors.¹⁵⁹ New practices have emerged to encourage and expand the practice of living donation, from both biologically and emotionally related donors. In addition to these traditional categories of living donors, two recent innovations include “nondirected donors” and various forms of exchanges between living donors and recipient pairs. Living nondirected donors are people who volunteer to donate one of their kidneys, usually anonymously, to the next available person on a waiting list at a transplant center.¹⁶⁰ Exchanges have taken two forms: in a “paired exchange,” two incompatible donor-recipient pairs exchange an organ with one another; in a “list-paired exchange,” the donor of an incompatible donor-recipient pair donates his or her kidney to the waiting list in exchange for the originally intended recipient being moved to the top of the UNOS waiting list.¹⁶¹ Although significant ethical concerns have been raised about list-paired exchanges, including whether such a system unfairly disadvantages candidates of blood type-O,¹⁶² the possibility of effectuating multiple paired exchanges across larger geographic regions is being aggressively explored.¹⁶³

Still, it is widely believed that even if each of these means of increasing the number of available organs is exploited in full, the vast disparity between demand and supply—and by extension the unsustainable waiting times for elderly patients—will only increase as a result of the demographic trends we previously discussed. For example, Spain, which has the best record of success in soliciting and procuring deceased-donor organs for transplantation, reports that an

159. The Organ Procurement and Transplantation Network Web site breaks down the numbers of deceased and living donors yearly at <http://www.optn.org/data>.

160. Patricia L. Adams et al., *The Nondirected Live-Kidney Donor: Ethical Considerations and Practice Guidelines*, 74 *TRANSPLANTATION* 582 (2002); James C. Gilbert et al., *The Nondirected Living Donor Program: A Model for Cooperative Donation, Recovery and Allocation of Living Donor Kidneys*, 5 *AM. J. TRANSPLANTATION* 167 (2005); Cheryl L. Jacobs et al., *Twenty-Two Nondirected Kidney Donors: An Update on a Single Center's Experience*, 4 *AM. J. TRANSPLANTATION* 1110 (2004).

161. See, e.g., Francis L. Delmonico et al., *Donor Kidney Exchanges*, 4 *AM. J. TRANSPLANTATION* 1628 (2004).

162. See Lainie F. Ross & Stefanos Zenios, Editorial, *Practical and Ethical Challenges to Paired Exchange Programs*, 4 *AM. J. TRANSPLANTATION* 1553 (2004).

163. See Inessa Kaplan et al., *A Computer Match Program for Paired and Unconventional Kidney Exchanges*, 5 *AM. J. TRANSPLANTATION* 2306 (2005).

average of 18% of those approached for permission refuse to donate.¹⁶⁴ Even if the rate of refusal could be improved in the United States, the estimated number of potential donors after brain death in this country is between 10,500 and 13,000.¹⁶⁵ Even a 100% rate of procurement, while helpful, would fail to keep up with the growth rate of ESRD and the transplant waiting list.

Although innovations in procuring organs from the living and the deceased are needed, it is far from clear that even these improvements will make much of a dent in the forecasted demand. After the number of living related and unrelated donors had doubled since 1995, the number has leveled off at approximately 6600 donors per year in the last two years.¹⁶⁶ The reasons for this lack of growth are unknown. On the deceased donor side, much of the recent growth in the total number of procured organs has come from extended-criteria donors.¹⁶⁷ As for donors after cardiac death, current projections predict only 2018 donors by the year 2013—a salutary contribution but quite modest compared to forecasted demand.¹⁶⁸ Though living non-directed donors have captured the attention of the popular media, such donations make up approximately 200 donations annually, and this number is not expected to increase substantially.¹⁶⁹ Finally, however welcome are the technological innovations that offer more kidneys to highly sensitized recipients, these advances do not tend to increase the total number of available organs for transplantation, or they make organs available that have been subject to aggressive immunosuppression, and the attendant complications are not tolerated well by elderly recipients.¹⁷⁰

164. Blanca Miranda et al., *Organ Donation in Spain*, 14 NEPHROLOGY DIALYSIS TRANSPLANTATION 15, 20 (Supp. III 1999).

165. Ellen Sheehy et al., *Estimating the Number of Potential Organ Donors in the United States*, 349 NEW ENG. J. MED. 667, 667 (2003).

166. Organ Procurement & Transplantation Network, Donors Recovered in the U.S. by Donor Type, <http://www.optn.org/data> (select "National Data" on left; then select "Donor" category; then select "All Donors by Donor Type" report) (last visited Feb. 12, 2007).

167. KIDNEY AND PANCREAS TRANSPLANTATION, *supra* note 12.

168. ORGAN PROCUREMENT & TRANSPLANTATION NETWORK, PROGRESS TOWARDS THE HRSA DONOR-RELATED PROGRAM GOALS 6 (2006), available at http://www.optn.org/SharedContentDocuments/Board_handout_sept2006_REVISED_OCT.pdf.

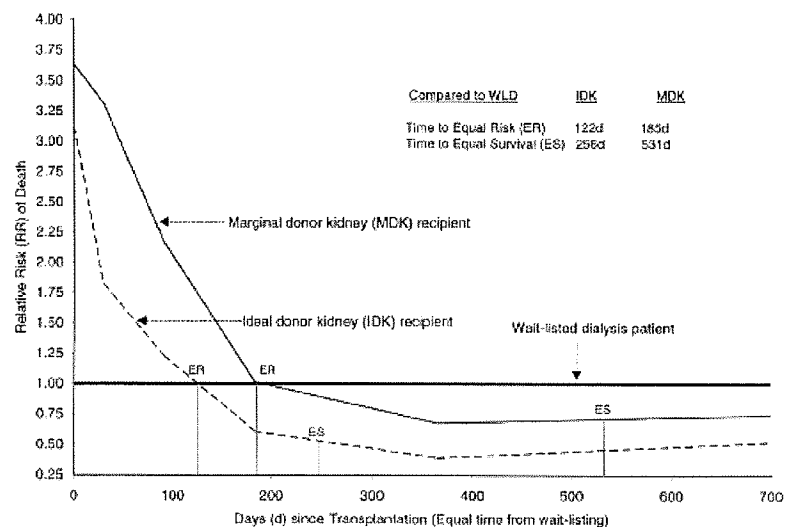
169. KIDNEY AND PANCREAS TRANSPLANTATION, *supra* note 12, at tbl.5.4c.

170. Bray, *supra* note 158; James M. Gloor et al., *Overcoming a Positive Cross-match in Living-Donor Kidney Transplantation*, 3 AM. J. TRANSPLANTATION 1017 (2003); Hippen, *supra* note 158.

The growing use of extended-criteria donor kidneys (referred to in the transplant literature as “marginal-donor” kidneys) is an effort to address the organ shortage that has special significance for elderly recipients. Organs from extended-criteria donors have higher rates of delayed function after transplantation and do not tend to last as long as organs from standard-criteria donors.¹⁷¹ Nonetheless, kidneys from marginal-donors are still superior to dialysis, though the survival benefit is not apparent until eighteen months after transplantation, compared to six months for a standard donor kidney, as Figure 3 illustrates.¹⁷²

Figure 3

Time After Transplant for Survival Benefit from Kidneys from Ideal Deceased Donors and Marginal Deceased Donors



Mounting anxiety over the shortage of organs has generated discussion about how best to allocate organs from extended-criteria do-

171. See Akinlolu O. Ojo et al., *Survival in Recipients of Marginal Cadaveric Donor Kidneys Compared with Other Recipients and Wait-Listed Transplant Candidates*, 12 J. AM. SOC'Y NEPHROLOGY 589 (2001); see also Farida Daikha-Dahmane et al., *Retrospective Follow-Up of Transplantation of Kidneys from 'Marginal' Donors*, 69 KIDNEY INT'L 546, 547 (2006).

172. Ojo et al., *supra* note 171, at 592 fig.1.

nors. Revising allocation methodology, of course, will not produce more organs, for it merely shifts the choice of who will remain on the list, and possibly die while waiting. Nonetheless, changing distribution guidelines might result in better use of available organs by directing them to patients who would derive the most benefit from them. In this context, "most benefit" would refer to years of life. To even contemplate allocating scarce organs according to social variables—a kidney to a young felon versus one to an elderly emeritus professor who is still teaching, perhaps—would put UNOS officials back on the treacherous road to Seattle and the "Life or Death Committee."

In 2004, in an effort to maximize survival benefit to recipients, UNOS revised its allocation rules for kidneys so that patients younger than eighteen are moved to the front of the line for high-quality organs from donors younger than thirty-five.¹⁷³ The agency did not implement any changes regarding the treatment of older patients based on how long they have been waiting to receive a compatible kidney. However, several recent studies have touted the potential benefits of "age matching" donors and recipients on grounds of potential efficiency, usually expressing the advantages in terms of the total number of life-years gained from "young-to-young" and "old-to-old" donor matching.¹⁷⁴ Whether elderly recipients benefit from such arrangements is dubious, however, and these proposals have been criticized as examples of age discrimination.¹⁷⁵ Under conditions of scarcity, utilitarian and egalitarian philosophies are destined to clash.

173. E-mail from Joel Newman, Assistant Dir. of Commc'ns, United Network for Organ Sharing, to Sally L. Satel, Resident Scholar, Am. Enter. Inst. (Feb. 6, 2007, 15:13 EST) (on file with author) ("Candidates younger than 18 do get preference over adults for kidneys from deceased donors younger than 35. It's not absolute priority, however. Circumstances as zero-antigen mismatches, high PRA candidates or deceased donor kidneys for a prior living donor would still be offered first. Of course there are not many kidney candidates younger than 11, but there are a few hundred adolescents.").

174. Herwig-Ulf Meier-Kriesche et al., *Kidneys from Deceased Donors: Maximizing the Value of a Scarce Resource*, 5 AM. J. TRANSPLANTATION 1725, 1726 (2005); see Bertrand L. Kasiske & Jon Snyder, *Matching Older Kidneys with Older Patients Does Not Improve Allograft Survival*, 13 J. AM. SOC'Y NEPHROLOGY 1067, 1067 (2002); Douglas S. Keith et al., *Effect of Donor Recipient Age Match on Survival After First Deceased Donor Renal Transplantation*, 15 J. AM. SOC'Y NEPHROLOGY 1086, 1086 (2004); Herwig-Ulf Meier-Kriesche et al., *Interaction Between Donor and Recipient Age in Determining the Risk of Chronic Renal Allograft Failure*, 50 J. AM. GERIATRICS SOC'Y 14, 14 (2002).

175. Jack J. Curtis, *Ageism and Kidney Transplantation*, 6 AM. J. TRANSPLANTATION 1264, 1264 (2006).

Blindness to old age is not the only factor compromising the utilitarian aim of maximizing the longevity of organ recipients. Giving priority according to time spent on the waiting list is also detrimental. Although a first-come, first-served policy is arguably fairer to recipients, the sad fact is that the longer people languish on the waiting list, the more they deteriorate medically and are therefore more likely to reject a new kidney. Moreover, dialysis may spur the immune system and increase the odds of rejecting a new kidney.¹⁷⁶ Consequently, medically deteriorating candidates will derive fewer years of life from a new kidney compared to other needy patients in better health. In short, waiting time is the inverse of survival benefit.

A 2007 UNOS meeting to discuss allocation policy¹⁷⁷ issued a draft proposal that would match kidneys to candidates in order to achieve the most years of transplant-enhanced life across the population.¹⁷⁸ Unlike the current allocation scheme, this new approach would consider age as a factor in determining organ distribution.¹⁷⁹ To help make these determinations, a resulting metric called "Life Years From Transplant" (LYFT) would calculate the difference between years gained from a transplant and the years afforded by dialysis.¹⁸⁰ Achieving this aggregate goal would mean markedly deemphasizing, if not completely omitting, time spent on the waiting list as a variable in allocation decisions.¹⁸¹ In short, kidneys would go to those who would live the longest rather than those who waited the longest.

The proponents of the life-years-from-transplant plan deny that a rigid age cut-off would be applied. Yet there is no question that because older candidates who have been on dialysis for many years do not enjoy as many extra years of life from transplantation as do their

176. Kevin C. Mange et al., *Effect of Use or Nonuse of Long-Term Dialysis on the Subsequent Survival of Renal Transplants from Living Donors*, 344 NEW ENG. J. MED. 726 (2001).

177. United Network for Organ Sharing, *Kidney Allocation Policy Development*, Public Forum in Dallas, TX (Feb. 8, 2007).

178. Robert Wolfe, Scientific Registry of Transplant Recipients, *Presentation Before United Network for Organ Sharing, Kidney Allocation Policy Development*, Public Forum in Dallas, TX: Predicting Life Years from Transplant (LYFT)—Focus upon Methods 32, 36 (Feb. 8, 2007), http://www.unos.org/SharedContentDocuments/KidneyAllocationSlides_Reduced.pdf.

179. *Id.* at 40.

180. *Id.* at 34.

181. *Id.* at 42 (stating that the inventory of variables used to calculate LYFT does not include time spent on the waiting list).

younger counterparts, their chances of receiving a transplant would decline. More precisely, 44% of candidates ages fifty to sixty-nine now receive a kidney, and nearly half of all kidneys go to those over fifty years of age.¹⁸² Under the proposed model, only about 20% of the fifty-to-sixty-nine age group would receive a kidney.¹⁸³ Looking at the far ends of the age spectrum, the percentage of kidneys going to patients in their twenties would rise from 6% under the current system to 19%.¹⁸⁴ Just 2.7% of kidneys would go to patients sixty-five and older, as compared with nearly 10% today.¹⁸⁵

Commentators have raised a number of questions. For example, will "transplant tourism" increase among the well-to-do elderly? Is the proposed system fair to the elderly who, relative to younger recipients, have paid more social security taxes over a lifetime? Will this allocation scheme be so demoralizing to candidates who have waited for years that they will just give up and die?

C. Brief History of the National Organ Transplant Act (NOTA)

In 1984, Congress passed the National Organ Transplant Act (NOTA),¹⁸⁶ which, among other things, mandated the development of a national organ procurement system to coordinate donated organs with recipients.¹⁸⁷ Prior to the establishment of a national registry, a number of major hospital centers were operating their own matching systems, along with three regional systems.¹⁸⁸ These systems were of little help to patients who lived outside the geographical area, and

182. Allan Leichtman, M.D., Scientific Registry of Transplant Recipients, Presentation Before United Network for Organ Sharing, Kidney Allocation Policy Development, Public Forum in Dallas, TX: Simulations Integrating a Measure of Life Years from Transplant (LYFT) into Deceased Donor Kidney Allocation 95, 116 (Feb. 8, 2007), http://www.unos.org/SharedContentDocuments/KidneyAllocationSlides_Reduced.pdf.

183. *Id.*

184. *Id.*

185. Laura Meckler, *More Kidneys for Transplants May Go to Young: Policy to Stress Benefit to Patient over Length of Time on Wait List*, WALL ST. J., Mar. 10, 2007, at A1.

186. 42 U.S.C. § 274e (2006).

187. *Id.*

188. Telephone Interview with Genel Myron, Professor Emeritus of Pediatric Endocrinology, Yale Univ. Sch. of Med., in Hartford, Conn. (Jan. 10, 2007).

they were becoming overwhelmed by the burgeoning demand for organs.¹⁸⁹

In the absence of a national network to match donors with recipients fairly and efficiently, patients had taken to private lobbying. Charles Fiske, a hospital executive in Bridgewater, Massachusetts, was one of the first desperate people to gain attention for his mission to find an organ. In October of 1982, Mr. Fiske stood before the American Academy of Pediatricians during its annual meeting at the New York Hilton and made a plea for his baby daughter's life.¹⁹⁰ Jamie Fiske was dying of biliary atresia,¹⁹¹ in which the bile ducts that normally discharge metabolic waste products do not develop; instead, the toxins remain in the liver and destroy it.¹⁹² Fiske was able to address the pediatricians only after lobbying assistance from Senator Edward M. "Ted" Kennedy (D-Mass.), House Speaker Thomas Phillip, Jr. "Tip" O'Neill (D-Mass.), and CBS Anchorman Dan Rather.¹⁹³ A *Time* magazine story called Fiske's efforts, which included advertising in a newsletter to emergency room doctors and telegrams to 500 pediatricians, "a remarkably skillful publicity campaign."¹⁹⁴ Fiske's campaign paid off when a Utah couple whose infant son was killed in a car accident saw the widespread media coverage of Fiske's speech, and eleven-month-old Jamie received their boy's liver.¹⁹⁵

Among the hundreds of letters Jamie Fiske received was a get-well note from President Ronald Reagan.¹⁹⁶ Indeed, the President took considerable personal interest in the issue of patients in need of organs.¹⁹⁷ "Once one is found, an Air Force jet is standing ready in case immediate commercial transportation is not available," he told

189. *Id.* In 1986, the contract to develop and implement the matching system went to UNOS, a nonprofit agency that was already one of three regional matching systems. United Network for Organ Sharing, History of the UNOS Database, <http://www.unos.org/data/about/history.asp> (last visited Feb. 12, 2007). By 1988, UNOS had expanded to national scope and still holds its monopoly contract with the Department of Health and Human Services. *Id.*

190. Claudia Wallis, *Which Life Should Be Saved?*, *TIME*, Nov. 22, 1982, available at <http://www.time.com/time/magazine/article/0,9171,955046,00.html>.

191. *Id.*

192. Medline Plus Encyclopedia, Biliary Atresia, <http://www.nlm.nih.gov/medlineplus/ency/article/001145.htm> (last visited Feb. 12, 2007).

193. Wallis, *supra* note 190.

194. *Id.*

195. *Id.*

196. *Reagan Note on Transplant*, *N.Y. TIMES*, Nov. 18, 1982, at B28.

197. *Backers of Organ Gifts Criticize Reagan Cuts*, *N.Y. TIMES*, Jan. 13, 1987, at C9.

the public in his July 23, 1983 radio address.¹⁹⁸ “The helicopter squadron at Andrews Air Force Base is alerted to transport Candi and her mother to Pittsburgh as soon as a suitable liver is found.”¹⁹⁹ The White House assigned an aide in Presidential Correspondence the task of helping patients secure Medicaid funding from their states to pay for transplantation surgery.²⁰⁰

Most of the patients whose stories came to the attention of the elite were in need of a liver. Though renal patients needed new kidneys—the demand for kidneys far outstripped the demand for livers and hearts—their plight was considered less dire because dialysis existed as a safety net. For patients with liver failure or cardiac failure, however, no temporizing technology existed. For them, getting an organ had the same life-or-death urgency that obtaining access to dialysis had for patients with renal failure prior to 1972. Also, most of the patients for whom public appeals were made were small children. Their inherent innocence and utter lack of culpability in their liver disease, combined with the palpable heartache for parents on the verge of losing a child, aroused keen public sympathy.

Parents of other sick children took their cue from Mr. Fiske’s successful publicity campaign, and scores of appeals went out to the media, the White House, and Congress.²⁰¹ In January 1983, just a few months after Jamie Fiske’s case captured national attention, Representative Albert Gore Jr. (D-Tenn.) was contacted via telegram by a family from his home state who sought his help in finding a liver for their child who had hepatic cancer.²⁰² This experience spurred Representative Gore’s interest in the problem of organ supply and distribution, and he went on to spearhead the issue in Congress.²⁰³ President Reagan, in parallel, brought the issue of the organ shortage

198. President Ronald Reagan, Radio Address to the Nation on the International Monetary Fund and on Organ Donorship (July 23, 1983), available at <http://www.reagan.utexas.edu/archives/speeches/1983/72383a.htm>.

199. *Id.* Candi, the eleven-year-old daughter of a White House electrician, was in need of a liver. *Id.*

200. John Iglehart, *Transplantation: The Problem of Limited Resources*, 309 *NEW ENG. J. MED.* 123, 126–27 (1983).

201. David L. Weimer, *The Puzzle of Private Rulemaking: Expertise, Flexibility, and Blame Avoidance in Regulations* 26 (La Follette Sch. of Pub. Affairs at the Univ. of Wisc.-Madison, Working Paper No. 2005-014, 2005).

202. The family was from the western part of the state and, in fact, not a constituent but had sent telegrams to the entire Tennessee delegation. Telephone Interview with Genel Myron, *supra* note 188.

203. Anne E. Kornblut, *A Father Recalls Gore’s Role in Saving Ailing Infant*, *BOSTON GLOBE*, Sept. 25, 1999, at A3.

to public consciousness, but he did not support federal involvement in organ acquisition and distribution.²⁰⁴

Gore was chairman of the House Subcommittee on Investigations and Oversight of the Committee on Science and Technology.²⁰⁵ In April of 1983, he held the first of several hearings on a proposed bill to establish a national registry and a mechanism to coordinate the collection and distribution of cadaver organs.²⁰⁶ Senator Orrin Hatch (R-Utah) and Senator Ted Kennedy (D-Mass.) crafted similar legislation and sponsored hearings in the Senate.²⁰⁷ President Reagan signed NOTA into law on October 19, 1984, despite administration opposition throughout the course of the deliberations.²⁰⁸ In less than two years, an impressively short period of time, organ policy went from concept to law.

Why were the early 1980s such an active chapter in the history of organ transplantation? After all, the first kidney transplant took place more than a quarter of a century earlier,²⁰⁹ and the first liver transplant was performed in 1963.²¹⁰ The answer, once again, was emerging biotechnology. Just as the invention of the Scribner shunt unleashed a vast demand for the treatment of ESRD, a pharmacological breakthrough in transplantation medicine—an immunosuppressant called cyclosporine A—launched a new era in organ transplantation.²¹¹ Compared to the previous antirejection regimen, cyclosporine was superior at protecting against acute rejection of the new organ, or “graft,” and carried fewer dangerous side effects, such as vulnerability to infection.²¹² Thus, by increasing graft and patient survival rates for all organs—kidney, heart, liver, lung, and pancreas—cyclosporine led to an increased demand for organs. The drug presented some toxicity problems of its own, but it catapulted transplantation to a new level of success and feasibility, thereby making the need for aggres-

204. Spencer Rich, *Organ-Donor Law Flouted, Senator Says; HHS Told to Award Contract by Dec. 15*, WASH. POST, Oct. 22, 1985, at A17.

205. Keith Mueller, *The National Transplant Act of 1984: Congressional Response to Changing Biotechnology*, 8 POL'Y STUD. REV. 346, 347 (1989).

206. *Id.* at 348.

207. S. 2048, 98th Cong. (1983); S. 1728, 98th Cong. (1983).

208. National Organ Transplant Act, 98 Pub. L. No. 507, 98 Stat. 2339 (1984) (codified as amended at 42 U.S.C. § 274e (2006)).

209. *First Kidney Transfer to Woman a Success*, N.Y. TIMES, May 25, 1953, at 13.

210. *Success Reported in Liver Transplant*, N.Y. TIMES, May 11, 1963, at 14.

211. Jamie Talan, *Scientist's Holiday Leads to New Drug*, N.Y. TIMES, Feb. 12, 1984, at 8.

212. *Id.*

sive recruitment of donors and efficient dissemination of organs even more pressing.

D. NOTA and the Market for Organs

Though coordination of distribution systems was by far the major goal of NOTA, it also contained a provision regulating the sale of organs from either deceased or living donors.²¹³ NOTA decreed that anyone who receives or gives “valuable consideration” in exchange for an organ could be convicted of a felony, with a maximum penalty of a \$50,000 fine and five years in prison.²¹⁴ The restriction on payment or in-kind exchange for an organ was prompted almost entirely by the activities of one man: a physician named Barry Jacobs of Reston, Virginia. In the fall of 1983, Jacobs, whose medical license was revoked five years earlier on a conviction for Medicare fraud, was making plans to establish an organ brokerage called the International Kidney Exchange.²¹⁵ “For a markup of \$2,000 to \$5,000, he would sell the organ to a patient needing a transplant to escape the tyranny of dialysis,” is how the *New York Times* described Jacobs’s enterprise.²¹⁶

In November 1983, Dr. Jacobs presented his plan to Gore’s subcommittee at a hearing entitled Procurement and Allocation of Human Organs for Transplantation.²¹⁷ To say that his testimony was not well received is an understatement, and he became the lightning rod for a general outcry against the idea of paying for organs.²¹⁸ This quickly led to Representative Gore’s insertion of a provision prohibiting payment for organs in his draft bill.²¹⁹ It became the most widely accepted feature of the bill—endorsed nearly unanimously, except by those who believed that the states, not the federal government, should determine policies of organ distribution.²²⁰ The antipayment provision was one of the few provisions to remain intact

213. 42 U.S.C. § 274e(a).

214. *Id.*

215. Donald Joralemon, *Shifting Ethics: Debating the Incentive Question in Organ Transplantation*, 27 J. MED. ETHICS 30 (2001), available at <http://jme.bmj.com/cgi/content/full/27/1/30>.

216. Nicholas Wade, *The Crisis in Human Spare Parts*, N.Y. TIMES, Oct. 4, 1983, at A26.

217. Mueller, *supra* note 205, at 350.

218. *Id.*

219. See Steve P. Calandrillo, *Cash for Kidneys? Incentives to End America’s Organ Shortage*, 13 GEO. MASON L. REV. 69, 79–80 (2004).

220. Mueller, *supra* note 205.

in the final version of the legislation.²²¹ According to Gore, organs should be assigned based on medical need, “not on who has the cutest face or the most money,” referring to personal appeals, including those by President Reagan, and to Dr. Jacobs’s scheme, respectively.²²²

Equal access to organs became the bedrock principle of American organ policy. According to Mark Fox, the former head of the UNOS ethics committee, “[t]he prisoner in California gets the heart transplant because he needs it and is first on the list. [The selection process is] blind to whether you’re a saint or a sinner or a celebrity. That’s key to maintaining the public trust.”²²³ Thus, the purpose of NOTA was two-fold: to ensure fairness in distribution of organs, and to prevent the wealthy or those with a public platform from jumping the queue ahead of other patients. However, effectuating these dual goals did not conflict with permitting valuable consideration in order to inspire more donations. The key issue was the source of that valuable consideration. If the federal government was the source, for example, then the rich would not be favored. Indeed, Gore himself said during deliberations in 1983 that providing incentives may be necessary.²²⁴

E. Altruism or Else

The principle of altruism as the sole legitimate impulse behind donation was now enshrined in law. But the concept that the civic act of donating one’s organs after death should be estranged from financial consideration can be traced to a vigorous debate in the 1960s and 1970s over whether the nation’s system of blood banks should continue their established routine of paying donors for blood. The controversy was ignited by Richard M. Titmuss, a professor of Social Administration at the London School of Economics, who had written

221. *Id.*

222. *Washington Talk: A Workable Organ Donor System*, N.Y. TIMES, Sept. 23, 1986, at A24.

223. *Id.*

224. *Hearing Before Subcomm. on Health and Environment of H. Comm. on Energy and Commerce*, 98th Cong. 10 (1983) (statement of Rep. Albert Gore, Jr., Member, House Comm. on Energy and Commerce) (“If the center judges efforts to improve voluntary donation are unsuccessful, consideration in progressing fashion would be given to the following: First, provision of incentives, such as a voucher system or tax credit for the donor’s estate; Second, a system of mandated choice such as requiring selection of donor status, yes or no, at time of driver’s license issuance. . . . Third, adoption of a system of presumed consent. . . .”).

widely about class inequality and was instrumental in shaping the British welfare state. In 1971, he published *The Gift Relationship: From Human Blood to Social Policy*, which became a best-selling book in the United States.²²⁵

Titmuss compared the efficiency of the U.K. and U.S. systems of blood procurement.²²⁶ He concluded that the free giving of blood within the British National Health Service was a more efficient way to collect and distribute blood than the practices of the American system, which were partly commercialized,²²⁷ a point raised several times during the House hearings in 1983. First, Titmuss noted, blood obtained from paid donors in the United States was more likely to be contaminated—given that the donor groups included alcoholics, injection drug users, and others at high risk for transmitted diseases, especially hepatitis.²²⁸ Second, Titmuss claimed that the idea of people giving their own blood away with no expectation of reciprocation encourages a sense of community.²²⁹

As to the first claim, part of the difficulty in assessing the relationship between the demographics of blood vendors and the risk of hepatitis was due to the absence of a reliable screening test for hepatitis in the 1960s and 1970s. Without empirical evidence, Titmuss's sociological generalizations about the relationship between commercial procurement of blood products and risk of infection with hepatitis B went unchallenged. As it happens, these generalizations turned out to be verifiably false. As economist Ross Eckert notes, blood collected from injection drug users and alcoholics was indeed more likely to be tainted with hepatitis, but this could be avoided by setting up collection sites in middle-class neighborhoods.²³⁰

There was also no guarantee that free blood would be cleaner than sold blood. When AIDS appeared in the early eighties, most of the infected blood came from gay men, a socially conscious group

225. RICHARD M. TITMUS, *THE GIFT RELATIONSHIP: FROM HUMAN BLOOD TO SOCIAL POLICY* (1977).

226. *Id.* at 11.

227. *Id.* at 196–97 (stating that paying for blood did not prevent 15% to 30% of blood collected in the United States from being wasted, while waste in the British voluntary system was infinitesimal during the same year).

228. *Id.* at 76.

229. *Id.* at 223–24.

230. Ross D. Eckert, *AIDS and the Blood Bankers*, 10 REG. 15, 20–21 (1986).

who volunteered blood regularly.²³¹ Today, donated blood is tested for HIV, hepatitis B, and hepatitis C, and contamination is rare, whether blood is paid for or not.²³² In addition, Titmuss's conflation of poverty with race served to buttress a pernicious ideology.²³³

Titmuss's second claim—that altruistic acts are among the most sensitive indicators of human relationships—retains some of its allure. A faithful socialist, Titmuss believed capitalism to be morally bankrupt:

[blood donors were] taking part in the creation of a greater good transcending the good of self-love. To "love" themselves they recognized the need to "love" strangers. By contrast, one of the functions of atomistic private market systems is to "free" men from any sense of obligation to or for other men regardless of the consequences to others who cannot reciprocate.²³⁴

Titmuss also believed that monetary incentives undermine a sense of civic duty and that citizens would not give blood at all if they could not give it freely.²³⁵ He arrived at this conclusion from the fact that the United States had more shortages of blood than did the United Kingdom.²³⁶ Whether such "crowding-out" occurs is ulti-

231. KIERAN HEALY, *LAST BEST GIFTS: ALTRUISM AND THE MARKET FOR HUMAN BLOOD AND ORGANS* 92 (2006). A tragic footnote: Professor Eckert, who was a hemophiliac, died in 1993 from one or several blood transfusions contaminated with hepatitis B and HIV. Karen Dillon, *Large-Scale Patient Search Founders While FDA Delays*, KAN. CITY STAR, Nov. 8, 2003, available at http://www.kansascity.com/mld/kansascity/news/special_packages/hepatitis/7208614.htm?template=contentModules/printstory.jsp.

232. See U.S. FOOD & DRUG ADMIN., DEP'T OF HEALTH & HUMAN SERVS., *KEEPING BLOOD TRANSFUSIONS SAFE: FDA'S MULTI-LAYERED PROTECTIONS FOR DONATED BLOOD* (2002), available at <http://www.fda.gov/opacom/factsheets/justthefacts/15blood.pdf>.

233. MICHELE GOODWIN, *BLACK MARKETS: THE SUPPLY AND DEMAND OF BODY PARTS* 8 (2006).

It is difficult to know whether Titmuss was leery of poor donors or poor "Negro" donors. In other words, Titmuss might have believed that all poor donors potentially placed blood supplies at risk. If so, his solution to forbid payments to poor donors addressed only one aspect of the tragedy he predicted, because poor donors were not excluded from altruistic blood donations. What Titmuss does make clear in his writings is that Negroes were potential polluters of the American blood supply.

Id.; see also HEALY, *supra* note 231 (giving a nuanced corrective to Titmuss's views on the relationship between organizational means of procurement (commercial versus altruistic) and safety).

234. TITMUS, *supra* note 225, at 239.

235. HEALEY, *supra* note 231, at 89.

236. *Id.*

mately an empirical question and tests of Titmuss's theory reveal a more complex picture than he envisioned.²³⁷

Surveys and social psychology experiments have found that subjects are less willing to participate, or they participate less strenuously, in a task they had already agreed to perform for free if it were to come with an offer of money.²³⁸ In these studies, subjects often expressed a sense that an otherwise acceptable or even admirable undertaking assumed a "taint" when a reward was offered or that they felt bribed.²³⁹ One proposed explanation of this phenomenon is that payment deprives the actor of the chance to signal to others that he is a charitable or civic-minded person.²⁴⁰ However, it may be possible to fulfill the actor's need to act altruistically if the reward is given to the needy.²⁴¹ Furthermore, there is some evidence that the lost altruistic donors deterred by offer of reward can be replaced by recruiting new donors, but only if the original offer is made more attractive.²⁴²

These observations are intriguing, but it is difficult to judge their predictive value when it comes to incentivizing organ donation. It is tricky, if not unwise, to extrapolate closely from subjects in contrived experiments with little at stake. Prospective donors contemplate a dramatic event with huge rewards for the recipient and substantial compensation for themselves. Would compensation crowd out the altruistic donors? Probably not, because the vast majority of living donors are friends or relatives of the recipient. Yet, even if some organ donor altruists were lost, the most important matter is whether their numbers would be replaced and exceeded by new recruits attracted by the possibility of remuneration. Thus, if the total number

237. See Douglas M. Surgenor & J. F. Cervený, *A Study of the Conversion from Paid to Altruistic Blood Donors in New Mexico*, 18 *TRANSFUSION* 54 (1978) (documenting the phenomenon of reverse crowding-out). When blood banks in New Mexico stopped offering payment for routine blood donation, there was a 100% donor turnover rate. See *id.*

238. HEALY, *supra* note 231, at 58–61; Uri Gneezy & Aldo Rustichini, *Pay Enough or Don't Pay at All*, 115 *Q.J. ECON.* 791, 791 (2000); Carl Mellström & Magnus Johannesson, *Crowding Out in Blood Donation: Was Titmuss Right?* 12–15 (Göteborg Univ., Dep't of Econ., Working Paper No. 180, 2006), available at <http://www.handels.gu.se/epc/archive/00004448/01/gunwpe0180.pdf>; Paul Seabright, *Blood, Bribes and the Crowding-Out of Altruism by Financial Incentives* (Feb. 8, 2002) (unpublished manuscript), available at http://idei.fr/doc/by/seabright/blood_bribes.pdf.

239. See, e.g., Gneezy & Rustichini, *supra* note 238, at 800–02.

240. See Seabright, *supra* note 238, at 17–18.

241. *Id.*; see also HEALY, *supra* note 231, at 58–61; Mellström & Johannesson, *supra* note 238, at 12–15.

242. Gneezy & Rustichini, *supra* note 238, at 798–800.

of transplantable organs increases, without an exorbitant increase in cost due to recruiting expense, then displacement of altruists is of minimal consequence to health policy.

F. Immoral Markets?

Some critics oppose organ sales based on the idea that money taints the fairness or parity of transactions. This view assumes the possibility, if not the certainty, that the seller has been coerced into acting against his better judgment or that he and his objectified body have been exploited. Are organs so precious as to be beyond valuation? What are the limits of commodification? In his essay, *What Money Can't Buy: The Moral Limits of Markets*, political philosopher Michael Sandel observes "the extension of markets and of market-oriented thinking into spheres of life once thought to lie beyond their reach."²⁴³ As examples, he cites the commodification of books, privatization of prisons, and the commercialization of governments and universities.²⁴⁴ Indeed, the kinds of practices that now involve valuation but were once considered immoral or repugnant have changed over the ages and will surely continue to evolve.²⁴⁵ For example, charging interest on loans was once considered repugnant.²⁴⁶ Moreover, legal scholar Martha Nussbaum points out that throughout European history, there was a "common aristocratic prejudice against earning wages."²⁴⁷ It was also considered inappropriate to pay female performance artists in Europe until the early nineteenth century.²⁴⁸ Yet today, Nussbaum notes, "few professions are more honored than that of opera singer. . . . Nor do we see the slightest reason to suppose that the unpaid artist is a purer and truer artist than the paid artist."²⁴⁹ Another example of changing views of valuation concerns the pricing of life itself. Life insurance was initially seen as the merchandizing of

243. Michael Sandel, Tanner Lecture Series on Human Values at Brasenose College: *What Money Can't Buy: The Moral Limits of Markets* (May 11 & 12, 1998), available at <http://www.tannerlectures.utah.edu/lectures/sandel00.pdf>.

244. *Id.*

245. Marion Fourcade & Kieran Healy, *Moral Views of a Market Society*, 33 ANN. REV. SOC. 1 (forthcoming 2007); Alvin E. Roth, *Repugnance as a Constraint on Markets* (Nat'l Bureau of Econ. Research, Working Paper No. 12702, 2006), available at <http://papers.nber.org/papers/w12702.pdf>.

246. Roth, *supra* note 245, at 4.

247. Martha C. Nussbaum, "Whether from Reason or Prejudice:" *Taking Money for Bodily Services*, 27 J. LEGAL STUD. 693, 697 (1998).

248. *Id.* at 694.

249. *Id.*

life, and the insurance industry, which started in the eighteenth century, floundered until around 1840, when it found acceptance and success as a way to aid widows and orphans.²⁵⁰

On the other hand, the notion that organs must be given altruistically is expressed forcefully by Leon Kass, former head of the President's Council on Bioethics. Accepting money in exchange for an organ, he writes, "repels us, quite properly I would say, because we sense that the human body especially belongs in the category of things that defy or resist commensuration—like love or friendship or life itself."²⁵¹ By "[s]elling our bodies," he writes, in reference to selling not our entire physical being but a discrete organ, "we come perilously close to selling our souls. There is even a danger in contemplating such a prospect; for if we come to think about ourselves as pork bellies, pork bellies we will become."²⁵²

This brings us back to Sandel's question about the moral limits of markets. We believe that the moral limits of markets are reached when the good in demand is rendered dysfunctional by the very act of its being paid for. That is why it is impossible to "buy" friendship, love, or passion. After all, none of those "items" function properly unless given freely. A kidney is different, as Sandel himself acknowledges in his brief consideration of the question of buying organs.²⁵³ Once transplanted, a kidney performs its essential functions of filtering waste from the blood and maintaining water and electrolyte balance whether or not it is paid for. A kidney is not integral to maintaining one's identity or freedom, so it is difficult to see how giving it up willingly, safely, and with full and informed consent compromises the giver in a significant way.²⁵⁴

Where does the public stand on the issue of payment for organs? Surveys demonstrate that people tend to be receptive to the idea. A random sample of jurors in Philadelphia found that incentives increased the intent to donate organs among those who had not planned to do so to a greater degree than incentives suppressed the intent to

250. Viviana Zelizer, *Human Values and the Market: The Case of Life Insurance and Death in 19th-Century America*, 84 AM. J. SOC. 591, 595-97 (1978).

251. LEON R. KASS, *LIFE, LIBERTY, AND THE DEFENSE OF DIGNITY* 193-94 (2002).

252. *Id.* at 195.

253. Sandel, *supra* note 243.

254. Benjamin E. Hippen, *In Defense of a Regulated Market in Kidneys from Living Vendors*, 30 J. MED. PHIL. 593, 598 (2005).

donate among those who already believed they would do so.²⁵⁵ A survey of dialysis patients found that they put a greater emphasis on increasing the supply of kidneys through incentives than on maintaining an altruistic system.²⁵⁶ A poll published in 2005 by researchers in Pennsylvania found that 59% of respondents favored the general idea of incentives, with 53% saying that direct payments would be acceptable.²⁵⁷ Among those who said that incentives would make a difference, the net effect was to encourage donation.²⁵⁸ Three older surveys found that a plurality, often more than half, were in favor of incentives as policy.²⁵⁹

A 2005 unpublished Gallup survey found that at least two-thirds of potential donors said incentives would have no effect on their decision to donate at death and that when incentives did influence respondents, there was no net change.²⁶⁰ In a 2006 study that surveyed family members who had been approached about donating the organs of a deceased loved one, 25% of respondents said that incentives, such as payment or coverage of funeral expenses, would have an effect on their decision to donate their own organs.²⁶¹ But the number of respondents encouraged to donate was offset by the number discouraged from donating by an offer of compensation.²⁶²

Today, Titmuss's ideological offspring inhabit bioethics committees and medical schools. A bedrock principle of UNOS is that

255. John David Jasper et al., *The Public's Attitudes Toward Incentives for Organ Donation*, 31 TRANSPLANTATION PROC. 2181, 2183 tbl.4 (1999).

256. Ashwini R. Seghal et al., *Dialysis Patients Attitudes Toward Financial Incentives for Kidney Donation*, 29 AM. J. KIDNEY DISEASES 410, 414 tbl.3 (1997).

257. Cindy L. Bryce et al., *Do Incentives Matter? Providing Benefits to Families of Organ Donors*, 5 AM. J. TRANSPLANTATION 2999, 3001 (2005).

258. *Id.*

259. UNITED NETWORK FOR ORGAN SHARING, PUBLIC ATTITUDES ON ORGAN DONATION: QUANTITATIVE RESULTS OF A UNOS/NKF STUDY 15 (1998) ("Nearly one in two consumers (48 percent) feel that some form of financial or non-financial compensation should be offered in the United States in an effort to increase the number of [deceased] organs available for donation. Forty-two percent oppose it, while 10 percent are undecided."); Astrid Guttman & Ronald D. Guttman, *Attitudes of Healthcare Professionals and the Public Towards the Sale of Kidneys for Transplantation*, 19 J. MED. ETHICS 148, 149 (1993) (noting that 70% of the general public favors compensation for kidneys from living donors); Dilip S. Kittur et al., *Incentives for Organ Donation?*, 338 LANCET 1441, (1991) (noting that 52% of respondents to a UNOS survey favor compensation for kidneys from deceased donors).

260. INST. OF MED., *supra* note 153, at 244.

261. James R. Rodrigue et al., *Attitudes Toward Financial Incentives, Donor Authorization, and Presumed Consent Among Next-of-Kin Who Consented vs. Refused Organ Donation*, 81 TRANSPLANTATION 1249, 1252 tbl.2 (2006).

262. *Id.*

"[o]rgan transplantation is built upon altruism and public trust. If anything shakes that trust, then everyone loses."²⁶³ In the end, however, the cost of pursuing Titmuss's vision of a noble act is to deny other people their very lives—a consequence that is almost surely true, given well-established economic principles, and one that professionals should at least have the chance to put to the test.

For years, frustrated physicians have tried to increase the number of organs. And, for years, most leaders of the transplant "community" rejected practically every suggestion and fledgling effort, charging innovators with violating principles of equality and altruism. Yet within the last few years, pleas for reform have grown more numerous and insistent. In a 2003 congressional subcommittee hearing, for example, the American Medical Association testified in support of pilot studies on increasing cadaver organs through incentives.²⁶⁴ Journals have published debates and commentaries; entities such as the President's Council on Bioethics, the Advisory Council on Transplantation of the Department of Health and Human Services, and the World Transplant Congress have discussed the issue.²⁶⁵ In 2006 alone,

263. The Gift of a Lifetime, The Organ Transplant Waiting List, <http://www.organtransplants.org/understanding/unos/> (last visited Feb. 12, 2007).

264. *Assessing Initiatives to Increase Organ Donations: Hearing Before Subcomm. on Oversight and Investigations of H. Comm. on Energy and Commerce, 108th Cong.* 51–54 (2003) (statement of Robert M. Sade, Member, American Medical Association's Council on Ethical and Judicial Affairs).

265. M. Abbud-Filho et al., *Payment for Donor Kidneys: Only Cons*, 70 KIDNEY INT'L 603 (2006); Kuldip P. Anand et al., *Thinking the Unthinkable: Selling Kidneys*, 333 BRIT. MED. J. 149 (2006); R. Cohen, *Organ Sales: Compromising Ethics*, 70 KIDNEY INT'L 608 (2006); Abdallah S. Daar, *The Case for a Regulated System of Living Kidney Sales*, 2 NEPHROLOGY 600 (2006); Francis Delmonico, Letter to the Editor, *The Transplant Donor Payment Debate*, 70 KIDNEY INT'L 605 (2006); Emma Dickinson, *What's Wrong with Selling Kidneys*, 333 BRIT. MED. J. 51 (2006); C.J. Diskin & D.L. Kaserman, Letter to the Editor, *The Transplant Donor Payment Debate*, 70 KIDNEY INT'L 604 (2006); Michael M. Friedlaender, *The Right to Sell or Buy a Kidney: Are We Failing Our Patients?*, 359 LANCET 971 (2002); Eli A. Friedman & Amy L. Friedman, *Payment for Donor Kidneys: Pros and Cons*, 69 KIDNEY INT'L 960 (2006); Eli A. Friedman & Amy L. Friedman, *Response to "Payment for Donor Kidneys: Only Cons,"* 70 KIDNEY INT'L 604 (2006); A.K. Glazier & Francis L. Delmonico, *Response to Conscription of Cadaveric Organs for Transplantation: Time to Start Talking About It*, 70 KIDNEY INT'L 607 (2006); Hippen, *supra* note 35; Benjamin E. Hippen & Robert S. Gaston, *The Conspicuous Costs of More of the Same*, 6 AM. J. TRANSPLANTATION 1503 (2006); Richard J. Howard, *Missed Opportunities: The Institute of Medicine Report: Organ Donation: Opportunities for Action*, 7 AM. J. TRANSPLANTATION 14 (2007); D.W. Landry, *Response to "Voluntary Reciprocal Altruism: A Novel Strategy to Encourage Decreased Organ Donation,"* 70 KIDNEY INT'L 606 (2006); M. Lifschitz, *Paying for Kidneys for Transplantation*, 70 KIDNEY INT'L 608 (2006); M.K. Mani, *Payment for Donor Kidneys*, 70 KIDNEY INT'L 603 (2006); Arthur J. Matas, *The Case for Living Kidney Sales: Ration-*

three academic books on the virtues of organ markets were published.²⁶⁶ According to Dr. Thomas Peters, one of the first transplant surgeons to write in favor of incentives for cadaver donation in the early 1990s, "the pendulum has swung, especially regarding discussion of paying living donors. It is no longer taboo."²⁶⁷ Dr. Richard Fine, president of the American Society of Transplantation, presented striking evidence of how far the debate has evolved in his address to the 2006 World Transplant Congress in Boston: "Is it wrong for an individual, who wishes to utilize part of his body for the benefit of another[, to] be provided with financial compensation that could obliterate a life of destitution for the individual and his family?" he asked his colleagues.²⁶⁸ "It is time that we cease to be pious about 'equity' in the acquisition of solid organs for transplantation."²⁶⁹

Yet one of the biggest advocacy groups for renal patients, the National Kidney Foundation, is strongly opposed to using incentives to increase the supply of deceased and living organs. According to foundation chairman Charles Fruit, "[f]amilies decide to donate the organs of a loved one for altruistic reasons. Payment is an affront to those who have already donated."²⁷⁰ In response, journalist Virginia Postrel, who is also the kidney donor to one of the authors, wrote on her Web site, "The argument that paying organ donors is 'an affront' to unpaid donors is disgusting. Are unpaid donors giving organs to save lives or just to make themselves feel morally superior? Even in

ale, Objections and Concerns, 4 AM. J. TRANSPLANTATION 2007 (2004); A.P. Monaco, *Rewards for Organ Donation: The Time Has Come*, 69 KIDNEY INT'L 955 (2006); Mary Simmerling et al., *The Commercialization of Human Organs for Transplantation: The Current Status of the Ethical Debate*, 11 CURRENT OPINION ORGAN TRANSPLANTATION 130 (2006); Aaron Spital, *Conscription of Cadaveric Organs for Transplantation: Time to Start Talking About It*, 70 KIDNEY INT'L 607 (2006); James S. Taylor, *Black Markets, Transplant Kidneys and Interpersonal Coercion*, 32 J. MED. ETHICS 698 (2006); D.J. Undis, Letter to the Editor, *Response to "Voluntary Reciprocal Altruism: A Novel Strategy to Encourage Decreased Organ Donation,"* 70 KIDNEY INT'L 606 (2006).

266. MARK J. CHERRY, *KIDNEY FOR SALE BY OWNER: HUMAN ORGANS, TRANSPLANTATION, AND THE MARKET* (2005); MICHELE GOODWIN, *BLACK MARKETS: THE SUPPLY AND DEMAND OF BODY PARTS* (2006); JAMES STACEY TAYLOR, *STAKES AND KIDNEYS: WHY MARKETS IN HUMAN BODY PARTS ARE MORALLY IMPERATIVE* (LIVE QUESTIONS IN ETHICS AND MORAL PHILOSOPHY) (2005).

267. Telephone Interview with Dr. Thomas Peters, Professor of Surgery, Univ. of Fla. Coll. of Med. (Jan. 3, 2007).

268. Richard N. Fine, President, Am. Soc'y of Transplantation, Presidential Address at the World Transplant Congress (July 19, 2006).

269. *Id.*

270. Charles B. Fruit, Letters to the Editor, *Should Kidneys Be Sold or Only Donated?*, WALL ST. J., May 23, 2006, at A17.

the latter case, they shouldn't care if other people get paid."²⁷¹ Such moral objections put us at a standoff. It is doubtful that Mr. Fruit will change his mind. And there is nothing he can say to dissuade us from believing that informed and willing individuals should be able to participate in an exchange involving valuable consideration. Thus, the meaningful question becomes one of compromise: how can both sides honor their moral commitments?

V. The Limits of Altruism and the Moral Imperative to Innovate

The best way to increase the supply of organs is to create a market arrangement to exist in parallel with altruistic giving. Within such a framework, any medical center or physician who objects to the practice of compensating donors may simply opt out of performing transplants that use organs donated under such circumstances. Recipients on the list would be similarly free to turn down a paid-for organ and wait for one given altruistically. Choice for all—donors, recipients, and physicians—would be enhanced, and it would be in the greater service of decreasing sickness and premature death. Paradoxically, the current system based on altruism-or-else undermines the respect for individual autonomy that is at the heart of the most widely held values in bioethics.

Another common objection to donor compensation is the potential for exploiting donors—especially low-income donors, who, as the critics reasonably claim, will be the most likely to find incentives attractive. Without question, protecting donors is enormously important. That is why any plan for compensation should be regulated. Potential donors must receive education about what it means to donate a kidney and the risks involved. They must undergo careful medical and psychological screening and receive quality follow-up care.

Critics often point to the horror stories from transplant black markets overseas and hold them up as cautionary tales. But the catastrophists have it exactly backward. It is when payment is not an above-board part of the medical system that black markets lead to

271. The National Kidney Foundation's Bad Math and Guilty Conscience, <http://www.dynamist.com/weblog/archives/002182.html> (last visited Feb. 12, 2007). For a donor who is offended by the idea of payment, see Michael Bourne, *The Power of the Selfless Gift*, BALT. SUN, Sept. 21, 2006, at 17A.

minimal education of prospective donors, poor postoperative and follow-up care, and failures to honor agreements for payment.

Incentive arrangements could apply to both deceased and living donors. Economist Lloyd Cohen proposed one of the first market-based models to increase the number of cadaver organs. Under this model, the incentive to join the current donor registry would either be a small payment, provided by the government or insurance companies, or the possibility of a much larger payment to the donor's estate should the organ be used at death.²⁷² The advantage of such a forward-looking approach is that the decision-making burden is removed from family members at a painful time—when they are sitting in the emergency room and learning that someone they love is now brain-dead. Without worry of exploiting the donor, a forward market could also help to satisfy the 23,000 people waiting for livers, hearts, and lungs.²⁷³ But deceased donors alone cannot meet the need for kidneys. Even if the rate of refusal could be drastically improved, supply is unlikely to meet demand; the estimated number of potential kidney donors after brain death in the United States is between 10,500 and 13,000.²⁷⁴

A. Incentive Schemes

To mitigate the shortage of kidneys, we must consider offering incentives to people while they are alive. There are several alternatives to achieve this goal.

1. THE CENTRALIZED SINGLE COMPENSATOR

Under the Centralized Single Compensator approach, the federal government or a designated agency acts as the only authority with the power to buy and allocate organs for transplants. As is currently the case with cadaver organs, kidneys obtained through compensated donors would be matched with the next best candidate waiting on the national list.

Medicare would underwrite the incentives, in light of the fact that it already pays for dialysis treatment under the 1972 ESRD

272. Lloyd Cohen, *Increasing the Supply of Transplant Organs: The Virtues of a Futures Market*, 58 GEO. WASH. L. REV. 1, 33 (1989).

273. Sally Satel, *Organs for Sale*, AMERICAN, Oct. 14, 2006, available at <http://www.american.com/archive/2006/november/organs-for-sale/>.

274. Sheehy et al., *supra* note 165.

amendment to the Social Security Act.²⁷⁵ This would make economic sense. A thirty-five-year-old patient spends about nine years on dialysis at a total cost of around \$600,000; a sixty-four-year-old patient spends about four years on dialysis at roughly \$300,000.²⁷⁶ Compare these expenses with the cost of transplantation. Arthur J. Matas and Mark Schnitzler analyzed the recurring annual cost of dialysis and compared it to the cost of a living-unrelated-donor transplant, including one-time procurement, transplantation, and postsurgical hospitalization costs, as well as the cost of immunosuppression for twenty years.²⁷⁷ The authors, a transplant surgeon and an economist, found the total cost of care during the first year after a living-donor transplant to be \$72,693 and the annual cost thereafter to be \$12,814.²⁷⁸ The break-even point between the cost of dialysis and transplantation is less than 1.5 years (\$101,259 for 1.5 years of dialysis versus \$85,507 after two years of transplantation and immunosuppression, based on the above figures), with cost-savings thereafter.²⁷⁹ The cost of three years of dialysis would pay for the entire cost of procurement, surgery, and the entire cost of immunosuppression for ten years.²⁸⁰ Furthermore, none of these figures takes into account expenditures adjusted for quality of life, an adjustment which would render even greater cost savings of transplantation relative to dialysis.

What kinds of compensation should be offered? A reasonable case could be made for an outright payment. After all, it is hard to argue that an individual is competent enough to sell an organ yet unfit to manage the money he receives in exchange for it. A compromise

275. See 118 Cong. Rec. S33003 (daily ed. Sept. 30, 1972) (statement of Sen. Hartke). This entitlement provides care for Americans with renal failure regardless of age if they have met required work credits for Social Security. Last year, the ESRD program spent about \$16 billion on dialysis, or about \$66,650 per patient annually, according to the United States Renal Data Service. 2006 ANNUAL DATA REPORT, *supra* note 5, at 384.

276. Arthur J. Matas & Mark Schnitzler, *Payment for Living Donor (Vendor) Kidneys: A Cost-Effectiveness Analysis*, 4 AM. J. TRANSPLANTATION 216, 219 (2003). The authors cite \$67,506 as the annual cost of dialysis, which results in \$607,554 for nine years of treatment and \$270,024 for four years of treatment. *Id.*

277. *Id.* at 218 tbl.1.

278. *Id.*

279. *Id.* at 219. At an annual cost of \$67,506, the cost for 1.5 years of dialysis would be \$101,259. The first-year cost of a transplant includes one year of immunosuppression. Thus a transplant, plus two years of immunosuppression would cost \$85,507 (\$72,693 + \$12,814). See *id.* at 218 tbl.1.

280. *Id.* The cost of dialysis over a three-year period would be \$202,518; a transplant and ten years of immunosuppression would cost \$188,019. See *supra* note 279.

approach could be adopted to defuse criticism that people will sell their organs for quick cash or use the cash to buy something frivolous. For example, the donor could choose from a menu of options including a deposit to a 401(k) retirement plan, tax credits, tuition vouchers for the donor's children, long-term nursing care, family health coverage, life and nonfatal injury insurance, a charitable contribution in the donor's name, or cash payments stretched over time.

Donor protection is the linchpin of any compensation model. Standard guidelines for physical and psychological screening, donor education, and informed consent could be formulated by a medical organization, such as the American Society of Transplant Surgeons, or by another entity designated by the federal Department of Health and Human Services. A waiting period of three to six months could be built in to ensure the prospective donor has ample time to think it through. Monitoring posttransplant donor health is important as well. One idea is to provide lifetime health insurance, through Medicare or a private insurer for the donor. The donor would receive annual physicals, routine medical screening, and long-term follow-up, in addition to standard health coverage. A federally sponsored registry of donors could help physicians study long-term outcomes for donors and take steps to remedy physical or psychological difficulties that arise.

2. MULTIPLE COMPENSATORS

In this scheme, an intermediary broker would coordinate donors, compensators (the entities that pay for the transplants), and medical centers. Medicare would be one of several possible compensators, along with private insurers, charitable foundations, and perhaps a fund established through a surcharge added to the cost paid by insurers and foundations.

3. PRIVATE CONTRACTS

The easiest way to start a market for organs is simply to change the law so as to allow someone who needs an organ and someone who wants to sell one to make their own arrangements through contract—as infertile couples currently do with surrogate mothers. But such a system would inevitably attract criticism because it appears to favor the rich over poor.

Although private contracts may seem unfair because only those with means will be able to purchase directly, poor people who need kidneys would be no worse off—and, very likely, considerably better off—than under the current system. There are several reasons for this effect. First, a stranger interested in selling a kidney is unlikely to give it away for free to the next person on the list (only seventy-two donors made such anonymous gifts in 2006²⁸¹); thus, few poor people would be deprived of kidneys they would otherwise have gotten. Second, anyone who gets a kidney by contract is removed from the waiting list and the subsequent people on the list benefit by moving up. Third, private charities could offer to help subsidize the cost for needy patients.

Under an enforceable private contract, a compensated donor would be treated no differently from an altruistic one. There would still be federal or state regulation. The donor would undergo rigorous medical and psychological screening at an established transplant center, receive guidance on informed consent, and have both a waiting period and the opportunity to drop out of the process at any point. No transplant center would dream of risking its reputation or loss of Medicare funding by failing to perform quality screening.

As for the argument that, despite all the safeguards, poor people will be tempted by money to sell a kidney they really want to keep, why not simply bar anyone with an annual income of under, say, \$35,000 from entering into such contracts? A variant on this approach, suggested by economist Steve Postrel, would be to give a one-year tax holiday to donors. That way, the rich would have a far bigger incentive to donate an organ than the poor.²⁸²

B. Questions Remain

These broad proposals and their variants need considerable elaboration. Many questions remain. How would prices be determined? Would each available kidney be allotted to the next well-matched person on the list? Or should living organs be preferentially

281. Organ Procurement and Transplantation Network, Transplant: Donor Relation by Transplant Year 2005–2006, <http://www.optn.org/data> (follow hyperlink “Build Advanced” on the left; then select “Transplant” category; then select “Donor Relation” category; then select “Transplant Year (2005–2006)” category; then specify “Kidney” as the organ) (last visited Feb. 12, 2007).

282. Interview with Steven R. Postrel, Assistant Professor, S. Methodist Univ. Cox Sch. of Bus., in Wash., D.C. (Mar. 11, 2006).

allocated to the healthiest people on the list—that is, those who will get the most “life” out of the organ? Could noncitizens be paid donors? Also, could potential donors have a say in who would receive their kidneys? As it currently stands, most living donors give altruistically because they are trying to help a friend or relative, not a stranger. But surely it is possible that the decision of an ambivalent friend could tip in the direction of giving with the promise of compensation. And because each patient on dialysis is functionally “attached” to a Medicare entitlement, perhaps the recipient could direct a portion of “his” Medicare allotment to a friend as payment for organ donation.

There is no denying the political and practical challenges that come with introducing payment into a twenty-year-old scheme built on the premise that generosity is the only legitimate motive for giving. Yet as death and suffering mount, constructing a market-based incentive program to increase the supply of transplantable organs has arguably become a moral imperative.

VI. Conclusion

Over its lifetime, dialysis has been subject to the extremes of allocation: rationing by social worth in its earliest days and, after 1972, wide availability through essentially unfettered access. As dialysis became more common and advances in immunosuppressant medication came about, more patients became eligible for a kidney transplant.

This set the stage for the National Organ Transplantation Act. The 1984 act established a national registry of transplant candidates and a system for matching and distributing organs.²⁸³ As the population seeking a new organ increased, the waiting time grew longer and longer, a phenomenon adversely affecting elderly candidates in particular for the simple reason that they might not survive long enough to receive a transplant. That reality was further complicated by the fact that dialysis, while undoubtedly life-prolonging, hastens the progress of cardiovascular disease, thereby imposing an added burden on older patients.

But another challenge arises when an older transplant candidate does live long enough to reach the top of the waiting list: will the eld-

283. See *supra* notes 186–87 and accompanying text.

erly donee get sufficient mileage from the new organ? It may seem like a harsh question, but the prevailing ethos among transplant experts—that an organ should be given to those who will derive maximum medical benefit from it—creates a problem for the elderly renal patient, whose claim to a new organ may be given relatively less weight.

Indeed, the tension between the medical needs of older patients with renal failure and the larger societal demand for rational allocation policy has raised controversial questions. Is a deceased-donor kidney being squandered when it is given to an elderly person instead of to a younger counterpart? Should older people have the same access to high-quality organs as younger candidates? How old is too old for transplant at all? Should the older patient instead remain on dialysis? Or should he be given an organ of marginal quality on the assumption that it will last “long enough”?

In 2007, we see again how remarkable advances in transplant medicine have reintroduced the classic dilemma of equity versus utilitarianism that beset the medical profession in 1962, after the advent of dialysis therapy. To be sure, the world of health care is no stranger to rationing—simply determining which pharmaceuticals are to be covered by health plans is a form of rationing—but rarely has case-by-case access to treatment been as overt as with rationing based on desired social characteristics in the early days of dialysis.

Unfortunately, the transplant experts tend to focus on distribution schemes to the near exclusion of contemplating dynamic ways to increase the numbers of organs. Would our plan to offer incentives work as we envision? There is good reason to be optimistic, but pilot studies are required to test various models. A larger pool of kidneys would alleviate the pressure of an anguished debate over whose life is to be dramatically enhanced, if not saved, through transplantation. Architects of any new plan must surely give serious consideration to principled reservations and to concerns about donor safety, but repugnance and anxiety are not in themselves arguments against innovation. We see them, more properly, as reasons for vigilance and care.