A PRIMER ON KIDNEY TRANSPLANTATION: ANATOMY OF THE SHORTAGE

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I

INTRODUCTION

Thousands of Americans die each year for lack of a suitable kidney donor. In this primer, we provide a quantitative description of the current shortage, and discuss future trends and possible solutions. We limit our primer to kidneys because, for reasons detailed in part II, the bulk of the U.S. waiting list and transplant activity involves kidneys, and because a variety of factors create opportunities to address the kidney shortage that are not feasible for most other organs.

The magnitude of the kidney shortage is indicated by the fact that in 2012, nearly 35,000 patients were added to the transplant waiting list (plus roughly 1400 candidates who needed both a kidney and a pancreas),¹ while there were only about 17,300 transplants—a gap of 17,700.² Thus, meeting the current need (not to mention reducing the length of the waiting list) would require more than doubling the current rate of transplants. Meanwhile, the waiting list continues to grow and currently stands at about 100,000.³ It would be far longer were it not for the fact that 5000 people on the waiting list die each year, and thousands of others are removed because they become too sick to receive a transplant.⁴

In this primer, we provide quantitative data and analysis in support of the

². See infra Figure 1 (Number of transplants in 2012 by organ).
⁴. See infra Figure 3 (Kidney transplants in 2012 by age-group and sex of recipients).
following principal conclusions:

1. The kidney shortage presents opportunities for life-saving interventions that are not possible with other types of organs.

2. The annual kidney shortage, as measured by additions to the waiting list, is currently about 21,000 per year. There are thousands more who would benefit from a kidney transplant but, given the vagaries of current waiting-list practices, are not deemed medically qualified.

3. The kidney shortage has grown rapidly and will continue to grow due to the continuing gap between need and supply.

4. There is not much prospect of increasing the flow of deceased donations, because most kidneys from potential donors who meet traditional criteria are already procured.

5. Living kidney donations are almost all directed, usually to family members.\(^5\)

6. Inducements could likely increase living donations—even directed donations.

Regarding this last point, it should be noted that financial inducements for donors are currently regulated by federal law. The relevant law, the National Organ Transplant Act (NOTA), enacted by Congress in 1984,\(^6\) prohibits the transfer of any human organ in exchange for “valuable consideration.” (It also establishes the Organ Procurement Transplantation Network (OPTN) to allocate deceased-donor organs.)\(^7\) Excluded from the definition of valuable consideration are the “reasonable payments associated with the removal, transportation, implantation, processing, preservation, quality control, and storage of a human organ or the expenses of travel, housing, and lost wages incurred by the donor of a human organ in connection with the donation of the organ.” As modified by the Charlie W. Norwood Living Organ Donation Act,\(^8\) NOTA now also specifically states that kidney-paired donation—that is, a case in which two or more patients with willing donors who are not good biological matches arrange a swap—does not involve valuable consideration.\(^9\)

NOTA does not define the phrase “valuable consideration,” and the precise meaning of the term is far from clear.\(^10\) But the statute is generally assumed to

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8. Id. § 274.
9. Id. § 274e.
11. Id.
12. See Kimberly D. Krawiec & Michael A. Rees, Reverse Transplant Tourism, 77 LAW &
prohibit a wide range of inducements to donate, including monetary payments to donors that go beyond reimbursement for out-of-pocket expenses. Many believe, however, that the time is right to reconsider the role of inducements. A rich array of possible incentive arrangements has been proposed in that regard, some of which are featured in this issue of Law and Contemporary Problems. In this primer we do not explore the menu of possibilities, but rather set the table for the discussion.

In part II we argue that kidneys are unique among the solid organs due to the combination of the low risk of living donation, the feasibility of extended waiting times while on dialysis, and Medicare coverage of dialysis and transplantation for kidney patients. Together these factors motivate the search for reforms that would increase the flow of living donors. In part III we demonstrate that kidney transplantation is less expensive and results in better health outcomes as compared to dialysis, and further explain the health advantages of living-donor kidneys over deceased-donor kidneys. In part IV we document the kidney shortage, demonstrating that the current system provides only about half as many kidneys as are needed for transplantation. The gap between need and supply was already evident when the data system of the United Network for Organ Sharing (UNOS) first went online in 1995, and has steadily widened over the years since then. In part V we discuss the current and future need for kidney transplantation, finding no reason to predict significant reductions in new additions to the waiting list. Part VI demonstrates the dim prospects for increasing kidney-donation rates under the current system: Donation levels have been static overall since 2006, and donations from living kidney donors have actually declined from their 2004 peak. Moreover, most kidneys from suitable deceased donors are already procured—even a perfect deceased-organ consent-and-allocation system would have yielded only about 5500 kidneys in 2011, not nearly enough to cover the roughly 21,000 kidneys that are needed per year to satisfy unmet demand. In part VII we conclude.

II
KIDNEYS AS A SPECIAL CASE

Kidneys differ from other organs in several important respects. First, because humans are born with two kidneys but need only one to survive, living donation is feasible. Although living donation is possible for other organs as well, the donor risks are higher than with kidney donation. In addition,
extended waiting times for those in need of kidney transplantation are medically feasible, due to dialysis, and financially feasible, due to Medicare coverage of end-stage renal disease (ESRD) treatment, which includes dialysis and kidney transplantation. In contrast, Medicare covers the treatment (including transplantation) of other organ diseases only if the patient already has Medicare due to age or disability.  

Figure 1 indicates that in 2012, 17,286 patients received a kidney transplant, including 801 who also received a pancreas transplant. Together, these patients constituted sixty percent of all individuals who received a solid-organ transplant during that year. Liver transplants were second, with just over twenty percent of all patients, while heart, lung, and other organs made up the rest. 

Medicare coverage of dialysis and transplantation for ESRD obligated the federal government to pay providers $34 billion in 2011, which amounted to 6.3% of total Medicare expenditures.  

Although ESRD expenditures have been growing rapidly, so has the overall Medicare budget. As a share of the total, ESRD expenditures grew from five percent in 1991 to six percent in 1999, and have remained at that level since then. 

Behind these figures lies a tale of the ordeals of individuals suffering from kidney failure. In most cases kidney failure is the culmination of chronic renal disease, a progressive loss of renal function that extends over months or years, and is usually caused by diabetes, high blood pressure, or glomerulonephritis. As renal function declines, waste products and excess fluid are excreted at a slower rate, with a variety of adverse medical consequences and an increasingly elevated mortality rate, especially from cardiovascular causes. If the disease progresses all the way to permanent kidney failure (stage five), then dialysis or a kidney transplant is required to sustain life. Typically a dialysis patient spends several hours at a dialysis center three times per week, although there


17. See id. at 328 fig.11.2.


are at-home alternatives. Dialysis can be compatible with a somewhat normal life, but the process imposes rigid structure, and is associated with a variety of medical side effects.\textsuperscript{20} For those who are healthy enough to endure the rigors of transplantation, a new kidney provides the hope of a better quality of life, as well as longer life expectancy, as detailed below in part III.\textsuperscript{21}

ESRD patients lucky enough to have a relative or friend who are willing to donate a kidney to them, and who are a close enough biological match, can proceed to transplantation directly, as do about 3000 patients per year.\textsuperscript{22} But most of the 115,000 new ESRD patients each year are put on dialysis\textsuperscript{23} and at some point may be screened for entry onto the waiting list for a kidney from a deceased donor.\textsuperscript{24} After extensive testing, patients who are deemed healthy enough to be candidates for transplantation are registered on one or more regional waiting lists.\textsuperscript{25} If a patient remains relatively healthy and stays on the active waiting list, the wait for a kidney from a deceased donor currently averages over four years, differing widely by region of the country, blood type, and other factors.\textsuperscript{26} Those patients who do receive a transplant (from either a living or deceased donor) can expect their lives to be improved but still difficult.\textsuperscript{27} They must take immunosuppressive drugs, which impair their immune system, and they are nonetheless at risk of graft failure. The “half-life” of a kidney graft for surviving patients is about thirteen years if from a living donor, and nine years if from a deceased donor.\textsuperscript{28} After a transplanted kidney stops functioning (due to graft failure or other reasons), the patient is placed back on dialysis, and perhaps back on the waiting list. About fourteen percent of patients on the UNOS waiting list have undergone a previous kidney transplant.\textsuperscript{29} As a group, their waiting time tends to be still longer than for first-

\begin{itemize}
\item \textsuperscript{20} See, e.g., DANIEL OFFER ET AL., DIALYSIS WITHOUT FEAR 3–28 (2007) (discussing the realities of life on dialysis).
\item \textsuperscript{21} See infra text accompanying notes 35–39 (discussing the advantages of transplantation over dialysis).
\item \textsuperscript{22} NAT'L. INST. OF HEALTH, 2013 ADR REFERENCE TABLES § D.1 http://www.usrds.org/2013/ref/D_modalities_13.xls (select tab “D.1”) (last visited Feb. 20, 2014) [hereinafter NAT'L. INST. OF HEALTH, 2013 ADR REFERENCE TABLES] (reporting number of patients starting with a transplant each year).
\item \textsuperscript{23} Id.
\item \textsuperscript{24} See Gabriel Danovitch, The Kidney Transplant Waiting List, UPToDATE, http://www.uptodate.com/contents/the-kidney-transplant-waiting-list (last updated Nov. 13, 2013). This waiting list is kept in the United States by UNOS.
\item \textsuperscript{25} UNITED NETWORK FOR ORGAN SHARING, QUESTIONS & ANSWERS FOR TRANSPLANT CANDIDATES ABOUT MULTIPLE LISTING AND WAITING TIME TRANSFER 2 (n.d.), available at https://www.unos.org/docs/Multiple_Listing.pdf.
\item \textsuperscript{26} See U.S. DEPT. OF HEALTH & HUMAN SERVS., UNITED STATES ORGAN TRANSPLANTATION: OPTN & SRTR ANNUAL DATA REPORT 2011, at 19 figs.KI 1.10 & KI 1.11 (2012) [hereinafter U.S. DEPT. OF HEALTH & HUMAN SERVS., OPTN & SRTR REPORT].
\item \textsuperscript{27} See generally Benjamin Hippen, The Case for Kidney Markets, NEW ATLANTIS: J. TECH. & SOC'Y, Fall 2006, at 47.
\item \textsuperscript{28} U.S. DEPT. OF HEALTH & HUMAN SERVS., OPTN & SRTR REPORT, supra note 26, at 34 fig.KI 6.7.
\item \textsuperscript{29} See Organ by Previous Transplant, U.S. DEPT HEALTH & HUM. SERVS.,
timers because in the process of rejecting their first kidney, they formed antihuman antibodies that make it harder to find compatible future kidney donors. 30

Figure 1: Number of Transplants in 2012 by Organ 31


III
THE CASE FOR LIVING DONATION

That living kidney donation is available at relatively little risk to the donor suggests there are opportunities to expand the kidney-donor pool that may not be available for other solid organs. As will be shown in part VI, the prospects for increasing the number of deceased-donor kidneys are limited, meaning that, barring major medical breakthroughs, any significant progress in closing the gap between kidney supply and need will have to come from living donations.

To be sure, living kidney donation is not risk free. The risk of death within ninety days of surgery is 3.1 per 10,000 donors, as compared to 0.4 per 10,000 in a matched nondonor cohort. To put this statistic into perspective, the reported surgical-mortality rate for laparoscopic cholecystectomy (gall-bladder surgery) is about 18 per 10,000 surgeries. Importantly, studies find no long-term increased risk of mortality among kidney donors.

These relatively low donor risks must be compared to the benefits of living kidney donation to recipients and to Medicare ESRD expenditures. First, kidney transplantation costs less than dialysis. To illustrate, data from the United States Renal Data System (USRDS) indicates that the per person per year Medicare costs of ESRD in 2011 (the last year for which data are reported) were $88,000 for hemodialysis, $72,000 for peritoneal dialysis, and $33,000 for transplantation (including immunosuppression). More importantly, a greater supply of donors would extend ESRD patient lives and improve their health, and this is especially true of living-donor kidneys, which last longer than deceased-donor kidneys.

The average life expectancy for a patient on dialysis is about five years. Dialysis can cause a variety of serious health complications, including anemia, bone disease, high blood pressure, heart disease, nerve damage, and infection. A kidney transplant extends life expectancy. Transplanted patients also report

33. Id. at 962. Two studies published as this article went to press suggest that the long-term risks of kidney donation—although still low—are higher for some donors than suggested by previous studies. Changes in the screening and eligibility of donors may reduce these risks. See Geir Mjøen et al., Long-Term Risks for Kidney Donors, 86 KIDNEY INTERNATIONAL 162 (2014); Abimereki D. Muzaale et al., 311 Risk of End-Stage Renal Disease Following Live Kidney Donation 579 (2014).
34. Id. at 963.
35. NAT’L. INST. OF HEALTH, 2 USRDS REPORT, supra note 16, at 328. It should be noted that the bulk of the cost for transplant occurs in the first year, and includes the cost of the organ procurement, surgery, and in-hospital care. After the first year, the bulk of the costs of maintaining a transplant are the cost of immunosuppressive medications. The annual $33,000 figure for transplant is an average over the first several years. See id. at 446.
37. Robert A. Wolfe et al., Comparison of Mortality in All Patients on Dialysis, Patients on Dialysis Awaiting Transplantation, and Recipients of a First Cadaveric Transplant, 341 NEW ENG. J.
a higher quality of life on several measures, as compared to dialysis patients, and are more likely to return to work than are dialysis patients. Moreover, living-donor kidneys function longer than deceased-donor kidneys: about twelve to twenty years on average, as compared to eight to twelve years for deceased-donor kidneys. A greater supply of donors would also decrease waiting times, producing additional health benefits. Because of long wait times, most patients do not receive transplants until they have been on dialysis for several years. However, time spent on dialysis can negatively affect a patient’s health even after transplantation, in part due to the long-term health problems caused by dialysis. Research shows that patients who spend two years on dialysis while waiting for a kidney transplant are three times more likely to lose the transplanted kidney than are those who wait on dialysis for six months or less. Best of all would be for patients to proceed directly to transplant following renal failure, but just 2.5% of new ESRD patients are transplanted before spending some time on dialysis. A recent study attempted to assess the overall effects of increasing the number of living kidney donations. The thought experiment was to offer a reward to living donors. If the offered payment increased living donations without decreasing deceased donations, the result would be to increase the transplant rate overall, reduce the wait time for a deceased-donor kidney, and of course increase the number of recipients who had the benefit of a kidney from a living donor. The authors estimated that if the rate of living donations increased, the wait time for deceased-donor kidneys would be reduced by at least ten years. The authors also estimated that if the rate of living donations increased by 2%, the wait times for deceased-donor kidneys would be reduced by at least five years. The authors concluded that increasing the rate of living donations would have a significant impact on the wait times for deceased-donor kidneys and would also improve the overall health outcomes for patients.

MED. 1725, 1725 (1999); The Benefits of Transplant Versus Dialysis, supra note 36. 38. The Benefits of Transplant Versus Dialysis, supra note 36. 39. Id. USRDS reports. Among patients who received a deceased donor kidney transplant in 2010, the probability of all-cause graft failure in the first year following transplant was 0.09, compared to 0.03 in those receiving a transplant from a living donor. The one-year graft and survival advantage experienced by living donor transplant recipients continues at five and ten years post-transplant, with [kidney failure] probabilities of 0.15 and 0.38 compared to 0.29 and 0.54 in those receiving a deceased donor transplant. NAT’L INST. OF HEALTH, 2 USRDS REPORT, supra note 16, at 289. 40. Organ Procurement and Transplantation Network Kidney Kaplan-Meier Median Waiting Times for Registrations Listed: 1999–2004, U.S. DEP’T HEALTH & HUM. SERVS., http://optn.transplant.hrsa.gov/latestData/step2.asp? (choose “Median Waiting Time” for category; choose “Kidney” for organ; then follow “Waiting Time by Blood Type” hyperlink) (last updated Feb. 14, 2014) (listing median wait times of between 597 and 2030 days, depending on blood type). 41. Herwig-Ulf Meier-Kriesche & Bruce Kaplan, Waiting Time on Dialysis as the Strongest Modifiable Risk Factor for Renal Transplant Outcomes, 74 TRANSPLANTATION 1377, 1377 (2002). 42. Michael Abecassis et al., Kidney Transplantation as Primary Therapy for End-Stage Renal Disease, 3 CLINICAL J. AM. SOC’Y NEPHROLOGY 471, 471 (2008). 43. See United Network for Organ Sharing, Financing a Transplant: Funding Sources, supra note 15. 44. See Lianne Barnieh et al., The Cost-Effectiveness of Using Payment to Increase Living Donor Kidneys for Transplantation, 8 CLINICAL J. AM. SOC’Y NEPHROLOGY 2165 (2013).
increased five percent in response to the reward, the result would be an increase of 0.11 quality-adjusted life years (QALYs) per person on the waiting list; if the rate of live donations increased twenty percent, the increase would be 0.39 QALYs per person.\footnote{Id. at 2165.}

In sum, dialysis is expensive and results in poor health outcomes for patients, with average life expectancy on dialysis being only five years. A successful transplant for a medically eligible patient is likely to improve health. The chance of success is greater if the transplant occurs soon after renal failure is established, and no matter when the transplant occurs, kidney transplants from living donors tend to yield better results than those from deceased donors. An increase in the number of living kidney donors could thus improve health outcomes for those with ESRD while reducing the annual cost per patient.

\section*{IV DOCUMENTING THE KIDNEY SHORTAGE}

As of November 2013, there were 99,000 candidates on the waiting list for a kidney transplant, and an additional 2000 waiting for a combination of kidney and pancreas.\footnote{Data, supra note 3.} The waiting list has increased linearly from about 30,000 in 1995 (the first year for which online data are available from UNOS).\footnote{See infra Figure 2.} This growth is the inevitable result of the flow of additions to the list exceeding the flow of removals throughout this period.

About one-third of those on the waiting list at any one time are inactive, meaning they are not available for an immediate transplant.\footnote{See U.S. DEPT. OF HEALTH & HUMAN SERVS., OPTN & SRTR REPORT, supra note 26, at 16 fig.KI 1.1.} Most with inactive status are too sick to tolerate a transplant, or have not completed the medical workup for a transplant. Other reasons for being inactive include cases in which the patient chooses to postpone the transplant, is obese, or, in a few cases, is deemed too well.\footnote{See id. at 16 fig.KI 1.3.} So long as they remain on the waiting list, however, those with inactive status still accumulate seniority and gain priority for receiving a transplant when a suitable kidney becomes available.

Table 1 documents the flows on and off the kidney waiting list for a single year, 2011. That year began with 85,082 on the waiting list, and during the course of twelve months increased by 2753 candidates. That increase was the difference between 29,040 net new additions to the list (ESRD patients who were deemed medically qualified for a transplant and remained on the list at the end of the year) and 26,287 patients who were removed during the course of the year. A majority of removals—16,089—were the result of transplants, but 5155 of those who were on the waiting list died, and others became too sick to be
transplanted.\textsuperscript{50}

\textit{Table 1: Accounting for flows on and off the kidney waiting list, 2011}\textsuperscript{51}

<table>
<thead>
<tr>
<th>Candidates waiting on January 1, 2011</th>
<th>85,082</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candidates added during 2011</td>
<td>29,040</td>
</tr>
<tr>
<td>Candidates removed during 2011</td>
<td>26,287</td>
</tr>
<tr>
<td>Transplant</td>
<td>16,089</td>
</tr>
<tr>
<td>Died</td>
<td>5155</td>
</tr>
<tr>
<td>Too sick</td>
<td>1904</td>
</tr>
<tr>
<td>Other removal</td>
<td>3139</td>
</tr>
</tbody>
</table>

| Candidates waiting on December 31, 2011 | 87,835 |

One reason that the waiting list has been growing is that patients with ESRD have been living longer even in the absence of a transplant.\textsuperscript{52} The growing pool of successful transplants also represents a source of demand because transplants generally fail within about ten years. Currently fourteen percent of the waiting list consists of patients who have previously received a kidney transplant.\textsuperscript{53}

Although the net increase to the kidney waiting list over the course of 2011 was 2753, that number is not a good measure of the gap between need and supply because, as noted above, it fails to account for those who die or become too sick for a transplant while on the waiting list. In order for need to be in equilibrium with the supply of kidneys for donation, there would have to be enough kidneys available to accommodate all new additions to the waiting list. In the ideal situation, all medically eligible patients would have a suitable transplant organ available within a few months instead of several years, as under the current regime. The result would be that few eligible patients would be lost to medical deterioration and death while on dialysis, and most all of

\textsuperscript{50} It should be noted that some patients are both added and then removed over the course of the year, and so they show up under both categories. Another way to do the accounting is to track all patients for one year who are on the waiting list as of January 1 of that year. For example, of the patients on the waiting list as of January 1, 2012, 14.5\% received transplants over the course of the year, 74.6\% were still on the waiting list at the end of the year, 5.1\% died before receiving a transplant, and 5.2\% were removed for various other reasons. E-mail from Sarah Taranto, UNOS Research Dept., to author Kimberly D. Krawiec (Oct. 28, 2013) (on file with author).

\textsuperscript{51} U.S. DEPT. OF HEALTH & HUMAN SERVS., OPTN & SRTR REPORT, supra note 26, at 18 tbl.KI 1.8, 37 tbl.KI 8.5. The statistics in this table combine the data for adult and pediatric cases. Patients who are listed, receive transplants, and then are relisted during the course of 2011 are counted more than once.

\textsuperscript{52} See U.S. DEPT. OF HEALTH & HUMAN SERVS., OPTN & SRTR REPORT, supra note 26, at 20 fig.KI 1.14.

them would actually receive a transplant. In that sense the need for kidneys for transplantation is equal to the flow of new additions to the waiting list, or roughly 35,000 per year at current rates, plus the 3000 or so who are transplanted before being put on the waiting list. By that definition, there are currently fewer than half as many kidneys for transplantation as needed, as illustrated by figure 2. In other words, the unmet need is on the order of 21,000 kidneys per year. The true number may be far higher, as we discuss in the next part.

Figure 2 provides a historical account of this gap between need and supply. That gap appeared when the UNOS data system first went online in 1995, and has widened in subsequent years. Between 1995 and 2006, flows (including both new additions and transplants) increased steadily, with the need increasing faster than the supply of kidneys available for transplantation. Since 2006 the need has continued to increase each year (albeit more slowly), but the rate of transplants has plateaued.

54. See NAT’L. INST. OF HEALTH, 2013 ADR REFERENCE TABLES § D.1, supra note 22 (roughly 3000 patients received transplants without going on waiting list); infra Figure 2 (Kidney waiting list additions and kidney transplants per year, 1995–2012).

55. In 2012, there were 16,485 transplants and 34,834 additions to the transplant waiting list. Others would have been added to the waiting list except that they received transplants before going on dialysis—the most recent count available is 2855 in 2011. So the relevant comparison is the number of cases newly qualified for a transplant (34,834 plus 2855) with the actual number of transplants (16,485). The difference is 21,204. See NAT’L. INST. OF HEALTH, 2013 ADR REFERENCE TABLES § D.1, supra note 22 (roughly 3000 patients received transplants without going on waiting list); infra Figure 1 (Number of Transplants in 2012 by Organ); infra Table 2 (Kidney waiting list additions by diagnosis, 1995 and 2012).

56. In fact the gap is even wider than depicted, because as noted above some of the transplants have gone to patients who were never on the waiting list.
Figure 2. Kidney waiting list additions and kidney transplants per year, 1995–2012

Figure 3 shows kidney transplants in 2012 by age-group and sex of the recipient. The number of transplants increases with age, up to around age sixty-five, with a drop-off thereafter. In every age-group, more men than women receive transplants. Not shown in this diagram is the breakdown by race: African American patients receive about one-quarter of all kidney transplants, despite constituting approximately one-eighth the U.S. population. Yet because ESRD is three-and-a-half to five times as common among black patients than white patients, the likelihood of transplant for black ESRD patients is lower than for white ESRD patients.

V

RECIPIENTS: THE CURRENT AND FUTURE NEED FOR KIDNEYS

Figure 3 shows kidney transplants in 2012 by age-group and sex of the recipient. The number of transplants increases with age, up to around age sixty-five, with a drop-off thereafter. In every age-group, more men than women receive transplants. Not shown in this diagram is the breakdown by race: African American patients receive about one-quarter of all kidney transplants, despite constituting approximately one-eighth the U.S. population. Yet because ESRD is three-and-a-half to five times as common among black patients than white patients, the likelihood of transplant for black ESRD patients is lower than for white ESRD patients.


Table 2 and figure 4 show the medical conditions leading to entry onto the waiting list in 1995 and 2012. Diabetes accounts for a large share of new entrants to the waiting list, growing from 27% of new entrants in 1995 to 32% in 2012. Hypertension follows, accounting for 21% of new entrants in 2012 (up from 17% in 1995). The remaining entrants suffer from a variety of medical conditions, including polycystic kidney disease, focal glomerular sclerosis, and IgA nephropathy. Table 2 also shows the growth in annual additions to the waiting list, from 17,258 in 1995 to 34,834 in 2012. The number of new entrants with diabetes and hypertension each more than doubled between 1995 and 2012.

Figure 4: Medical conditions leading to entry onto the waiting list

Table 2: Kidney waiting list additions by diagnosis, 1995 and 2012

<table>
<thead>
<tr>
<th>Condition</th>
<th>1995</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>3012</td>
<td>7336</td>
</tr>
<tr>
<td>Diabetes</td>
<td>4593</td>
<td>11,201</td>
</tr>
<tr>
<td>Other</td>
<td>9653</td>
<td>16,297</td>
</tr>
<tr>
<td>Total</td>
<td>17,258</td>
<td>34,834</td>
</tr>
</tbody>
</table>

62. See infra Table 2. Hypertension includes hypertensive nephrosclerosis and malignant hypertension. Diabetes includes both type I and type II diabetes. The top three diagnoses in the “other” category are polycystic kidney disease, focal glomerular sclerosis, and IgA nephropathy.

Changes in the future need for kidneys will be driven by several factors. One underlying trend of interest is the incidence of new ESRD patients, which has been stagnant in recent years at about 115,000. Only about one-third of these newly diagnosed patients end up with a transplant or on the waiting list for a transplant, and if that fraction increases (due, for example, to changes in wait-listing practice or to medical progress that improves the health of ESRD patients, hence making them better candidates for a transplant), then it could still be true that transplant need would increase as well. Since 2006, however, there has been little increase in the rate at which patients are added to the waiting list (as shown in figure 2).

There is considerable evidence of inconsistency in the process by which ESRD patients are qualified for the transplant waiting list. One study found that many newly diagnosed patients were not placed on the waiting list, despite being healthier (in the sense of having a longer life expectancy on dialysis) than those who were placed on the waiting list. The Agency for Healthcare Research and Quality estimated that an “achievable benchmark” for transplant eligibility was ten percentage points higher than the current national average. A consistent evidence-based standard applied in every locality could help achieve that goal. Thus, the current flow of patients onto the waiting list could increase substantially, not because of an increase in the number of new ESRD patients, but because of a change in the process of medical qualification.

VI

PROSPECTS FOR INCREASING THE NUMBER OF DONORS

Figure 5 shows trends in kidney donation since 1988. Several trends in figure 5 are worth noting. First, the number of deceased donors has exceeded the number of living donors, except for the years 2000 through 2005. (The number of deceased-donor kidneys, represented by the dashed line in figure 5, is about twice as high as the number of deceased donors, because most deceased donors yield two transplantable kidneys.) Second, overall donations were growing from 1988 to 2005, but have been static since then. That is the net result of somewhat different trends in deceased and live donations. The number of deceased donors

64. Kam Kalantar-Zadeh, The Future of Dialysis in the U.S., RENAL & UROLOGY NEWS, Oct. 1, 2013, at S4. This generally stagnant rate of new ESRD patients masks significant differences across age and ethnic groups. For example, in older populations (aged 60 and older), ESRD rates associated with diabetes have declined for African Americans, Native Americans, and Hispanics but have increased for whites aged 70 and older. Allan J. Collins et al., The State of Chronic Kidney Disease, ESRD, and Morbidity and Mortality in the First Year of Dialysis, 4 CLINICAL J. AM. SOC’Y NEPHROLOGY S5, S6 (2009). In the age-group 20–39, however, diabetes incidence rates continue to rise for African Americans and Native Americans. Id.

65. J.D. Schold et al., The Overlapping Risk Profile Between Dialysis Patients Listed and Not Listed for Renal Transplantation, 8 AM. J. TRANSPLANTATION 58, 63 (2008) (linking various characteristics of healthier patients to a disproportionately higher likelihood of not being listed).

trended upward from 1988 to 2005, but has plateaued since then, rising only slightly through 2012. The number of living kidney donors increased from 1988 to a high in 2003, then decreased through 2012. That downturn is surely a matter of concern, but one for which we have no explanation.

In considering where to look for more kidneys, we begin with the basic demographics: As shown in figure 6, all donors under age 18 are deceased, and there are few donors living or deceased over age 64. In 2012, the peak age-group for deceased donation was 18–34, whereas the peak age-group for living donation was 35–49.

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The fact that younger adults have the highest rate of deceased donation is related to the criteria for kidney donation. The medical challenge for any transplant team is to identify people who are about to die but are young enough and healthy enough in relevant respects to provide disease-free, durable kidneys that can be recovered in controlled circumstances (almost always in a hospital) immediately after death. The standard criteria for a deceased kidney donor is a patient who is declared brain-dead in a hospital while the heart is still beating, who is aged sixty or less, and who does not suffer from any of a number of identified medical conditions. (The medical criteria are somewhat looser for patients under age fifty.) “Expanded” criteria for deceased kidney donation includes otherwise healthy donors with brain death after age sixty, although transplant centers reject kidneys from these donors about forty percent of the time. There are also about 1000 cardiac-death donors each year.


70. See Julio Pascual et al., A Systematic Review of Kidney Transplantation From Expanded Criteria Donors, 52 AM. J. KIDNEY DISEASES 553, 553 (2008).

71. Id. at 558. OPTN and UNOS recently approved amendments to OPTN policy that replace the definitions of standard-criteria and extended-criteria donor with the kidney donor profile index, a
year—patients who are pronounced dead when their heart stops beating, rather than as a result of cessation of brain function—but they too tend to be younger patients who lack comorbidities.  

The typical criteria that are applied to identifying suitable deceased donors have the effect of disqualifying all but a small fraction of the 2.5 million people who die each year. Table 3 provides some detail on this winnowing process for 2010, gathered by sorting the 2.5 million records from the National Vital Statistics Multiple Cause Mortality Dataset according to particular fields in the electronic records, beginning with age. We begin with the fact that almost two-thirds of all deaths are of persons over seventy, such that the decedents are almost always deemed medically unacceptable due to age alone. Of the remainder, most die in uncontrolled settings out of the hospital, or in the hospital from causes like cancer, diabetes, and renal disease that ordinarily are disqualifying. In 2010 only about 9000 deaths were “eligible” by either the standard criteria or expanded criteria, and in seventy percent of those cases the kidneys were in fact donated. In addition, 928 others became donors after cardiac death, which is uncommon because it is a difficult procedure—once the heart stops beating, the kidneys deteriorate rapidly. Still, all hospitals that accept Medicare now have donation-after-cardiac-death protocols, and it is an expanding practice.

One lesson from these statistics is that even an organ consent-and-allocation system with 100% compliance would have yielded only an additional 2751 donors, or roughly 5500 kidneys. This is not nearly enough to satisfy current need, which is about 21,000 even counting just new cases per year—and is even greater if the backlog is included.

formula designed to classify kidneys based on estimated years of function posttransplant. Transplant professionals already have access to this formula and, according to OPTN, the change “does not affect the decision-making process between an individual candidate and his or her transplant team regarding kidney offers they would be willing to accept for a transplant.” OPTN/UNOS Board Approves Significant Revisions to Deceased Donor Kidney Allocation Policy, U.S. DEP’T HEALTH & HUM. SERVS. (June 25, 2013), http://optn.transplant.hrsa.gov/news/newsDetail.asp?id=1600.

72. See infra Table 3.


74. See infra Table 3.

Table 3: The winnowing process for deceased donors, 2010

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total deaths</td>
<td>2,468,435</td>
</tr>
<tr>
<td>– Deaths &gt; age 70’</td>
<td>(1,608,440)</td>
</tr>
<tr>
<td>= Deaths ≤ age 70’</td>
<td>859,995</td>
</tr>
<tr>
<td>– Deaths out of hospital’</td>
<td>(547,123)</td>
</tr>
<tr>
<td>= Deaths ≤ age 70 and in hospital’</td>
<td>312,872</td>
</tr>
<tr>
<td>– Medically unsuitable deaths*</td>
<td>(176,451)</td>
</tr>
<tr>
<td>= Potentially eligible deaths’</td>
<td>136,421</td>
</tr>
<tr>
<td>– Deaths excluded due to other medical conditions or circulatory death’</td>
<td>(127,357)</td>
</tr>
<tr>
<td>= Eligible deaths (as reported by OPOs)**</td>
<td>9,064</td>
</tr>
<tr>
<td>– Not recovered (no consent, etc.)’</td>
<td>(2751)</td>
</tr>
<tr>
<td>= Kidney donors (SCD and ECD)</td>
<td>6,313</td>
</tr>
<tr>
<td>+ Recovered kidney donors (DCD)</td>
<td>928</td>
</tr>
<tr>
<td>= Total kidney donors’</td>
<td>7241</td>
</tr>
</tbody>
</table>

Legend
OPO = Organ-procurement organization
SCD = Standard-criteria donor
ECD = Expanded-criteria donor
DCD = Donation after cardiac death

a. Original calculations are from the National Vital Statistics multiple cause mortality dataset. *Vital Statistics Data Available Online, supra note 73. See generally Murphy, supra note 7370.*
b. Computed by subtracting “medically unsuitable deaths” from “Deaths <= 70 and in hospital, as shown.”
c. Computed as the difference between “Potentially eligible deaths” and “eligible deaths (as reported by OPOs).”
e. Computed as difference between “eligible deaths” and “recovered kidney donors”

*Includes the following codes from the tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10): Certain infectious and parasitic diseases (A00-B99); Malignant neoplasms (C00-C42, C45-C68, C73-C79); Diabetes mellitus (E10-E14); Hypertension with renal insufficiency or renal failure (I12-I15); Renal disease (N00-N29). Based on Akinlolu O. Ojo et al., *A Practical Approach to Evaluate the Potential Donor Pool and Trends in Cadaveric Kidney Donation, 67 TRANSPLANTATION 548 (1999).*

Given that younger adults who are quite healthy in most respects make the best candidates for deceased donation, it is not surprising that traumatic deaths are a relatively important source of deceased-donor kidneys. Figure 7 shows that in 1995, almost half of deceased donors (forty-five percent) died from a motor-vehicle accident, homicide, or suicide. By 2012, the number of donors who died in motor-vehicle accidents had declined somewhat and the percentage from all three of these causes had declined from 45 to 32. The relative decline in homicide and motor-vehicle donors tracks the good-news story that the overall number of deaths from both causes has declined substantially since 1991: During that time, the number of motor-vehicle deaths declined from 43,631 to 35,498, while the homicide count declined from nearly 26,513 to 16,671. But this news, while unequivocally good on balance, nonetheless has the unfortunate consequence of reducing one important source of deceased donors.

Figure 7: Causes of death for deceased kidney donors


In sum, the prospect for substantial increases in deceased kidney donation is dim. Although some suitable donors are lost due to refusal by transplant centers or mismanagement, the most that could be gained from reducing those losses is about 5000 additional kidneys per year. Medical science may progress to the point of being able to salvage more organs from cardiac deaths and patients whose age or medical history currently disqualifies them, but expanding on those margins is likely to result in additional post-transplant problems. The ready-at-hand solution is to expand the number of living donors, but in the face of the recent decline in living donations, that will require a new approach.

All but 182 living donations in 2012 were directed to specific patients, in most cases to members of the immediate family (figure 8). That pattern is not surprising given that donation is a major medical procedure with some risks, and that living donors are not compensated financially. Most are unwilling to make such a considerable sacrifice for strangers. Indeed, the usual account of living donation as altruistic perhaps creates the wrong impression. This is largely a family matter.

**Figure 8: Recipient relationship to live donor, 2012**

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If NOTA were amended to allow financial rewards to living donors that went beyond the currently permitted compensation for lost wages, housing, and travel, it seems reasonable to suppose that the result would be an increase in living donations, both directed and undirected. The experience of Iran, as well as evidence from the black market (not examples we wish to follow, to be sure) provide support for this contention, as do studies of financial rewards in related contexts, such as blood donation.\footnote{See Gary S. Becker & Julio Jorge Elias, Introducing Incentives in the Market for Live and Cadaveric Organ Donations, J. ECON. PERSP., Summer 2007, at 3 (2007) (estimating the price at which financial incentives would reduce the kidney waiting list). The Iranian model of compensated organ donation has reportedly eliminated waiting lists, but created other problems, including a lack of donor follow-up care. See, e.g., Ahad J. Ghods & Shekoufeh Savaj, Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation, 1 CLINICAL J. AM. SOC’Y NEPHROLOGY 1136, 1139 (2006).}

We do not want to suggest that financial rewards are the only way to increase living donation. Perhaps with enough resources and creativity, an effective marketing strategy could be devised that would better educate the public about the need and the risks. Indeed, a campaign of that sort may well be worthwhile even if a financial reward were introduced. Any major innovation or combination of innovations in this area should be introduced on a limited basis with an experimental mindset, because at present we can only speculate about consequences.

VII

CONCLUSION

In this primer, we have presented a quantitative analysis of the kidney shortage, with a tentative projection of future trends. That analysis provides insights into the nature of the kidney shortage and illustrates why many researchers and policy makers are now converging on inducements as a possible solution.

The most important of these insights is the realization that improvements to the deceased-donor consent-and-allocation system will not eradicate the kidney shortage. As this primer demonstrates, current unmet need stands at about 21,000 kidneys per year and even a perfect deceased-donor consent-and-allocation system would produce only an additional 2751 donors, or roughly 5500 kidneys, per year. Those additional kidneys would be welcome but not nearly enough to satisfy current need, meaning that—barring a major breakthrough in recovering organs from patients who are currently deemed unsuitable—increasing donations from living donors is the only plausible means to close the gap. We do not mean to suggest that efforts to increase rates of deceased organ donation are not worthwhile or should be abandoned. Our

\begin{itemize}
  \item \footnote{See, e.g., Nicola Lacetera et al., Will There Be Blood? Incentives and Displacement Effects in Pro-Social Behavior, 4 AM. ECON. J. ECON. POL’Y 186, 186 (2012) (presenting evidence from roughly fourteen thousand American Red Cross blood drives and concluding that “economic incentives have a positive effect on blood donations without increasing the fraction of donors who are ineligible to donate”).}
\end{itemize}
point is simply that such efforts are likely to satisfy only about a quarter of current unmet demand.

Living kidney donations will therefore have to make up the rest of the needed supply of kidneys, leading to our second insight: Living kidney donations are currently nearly all directed, usually to family members. Perhaps with sufficient education and public outreach, the number of altruistic donors could be increased. But it is not encouraging that there were only 182 nondirected donors in 2012, and that there is a recent downward trend in living donations, despite current education and outreach efforts.

For all of these reasons, we believe the time is ripe to reconsider inducements to kidney donation, and financial inducements in particular. Needless to say, a system that provided financial rewards for living donors could produce unsavory consequences, and would have to be carefully designed and managed. But without such a system, the most likely version of the future is a continuation of unnecessarily high rates of death and disability from kidney failure.