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 1,400 candidates who needed both kidney and pancreas), while there were only about 17,300 transplants – a gap of 17,700. Thus, meeting 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. It would be far larger were it not for the fact that 5,000 people on the waiting list die each year, and thousands of others are removed because they become too sick to be transplanted.

In this primer, we provide quantitative data and analysis in support of the following principal conclusions:

- Kidneys present a special case with potentially unique opportunities for life-saving interventions.
- 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 waitlist practices, are not deemed medically qualified.

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2 OPTN, Waiting List Additions Age by Listing Year, For Organ = Kidney / Pancreas and Organ = Kidney, Count = Candidates (Based on OPTN data as of October 25, 2013).

3 See infra Figure 1, Number of Transplants in 2012 by Organ.


5 See infra Figure 3.
• The kidney shortage has grown rapidly and will continue to grow due to divergent trends in need and supply.
• There is not much prospect of increasing the flow of deceased donations, since most kidneys from potential donors who meet traditional criteria are already procured.
• Living kidney donations are almost all directed, usually to family members.
• 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. That law, the National Organ Transplant Act (PL 98-507) (“NOTA”), was enacted by the US Congress in 1984, and 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.) 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.”\textsuperscript{6} As modified by the Charlie W. Norwood Act, NOTA now also specifically excludes from the definition of valuable consideration kidney paired donation -- that is, cases in which two or more patients who have willing donors that are not good biological matches arrange a “swap.”\textsuperscript{7}

NOTA does not define the phrase “valuable consideration” and the precise meaning of the term is far from clear.\textsuperscript{8} But the statute is generally assumed to 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 have been proposed in that regard. In this primer we do not explore the menu of possibilities, but rather set the table for the discussion.

Part II argues 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 transplant for kidney patients. Together these factors motivate the search for reforms that would increase the flow of living donors. Part III demonstrates that kidney transplantation is less expensive and results in better health outcomes as compared to dialysis, and further explains the health advantages of living donor kidneys over deceased donor kidneys. Part IV documents 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

\textsuperscript{6} National Organ Transplant Act (PL 98-507) §301(c)(2).
\textsuperscript{7} Charlie W. Norwood Living Organ Donation Act.
\textsuperscript{8} Kimberly D. Krawiec & Michael A. Rees, Reverse Transplant Tourism, THIS VOLUME (discussing the potential reach of NOTA’s ban against valuable consideration in exchange for transplantable human organs).
supply was already evident when the UNOS data system first went on line in 1995, and has steadily widened over the years since then. Part V discusses 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 2003 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; not nearly enough to cover the roughly 21,000 kidneys that are needed per year to satisfy unmet demand. Part VII concludes.

II. Kidneys As A Special Case

Kidneys present a special case for several reasons. 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, including 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. Together, these patients constituted 60% of all individuals who received a solid-organ transplant during that year. Liver transplants were second, with just over 20% 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. While ESRD expenditures have been growing rapidly, so has the overall Medicare budget. As a

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9 See infra Table 1 (calculating this figures).
10 Living donors can donate one of two kidneys, one of two liver lobes, or part of the lungs, pancreas, or intestines. Counterintuitively, living donation of a heart sometimes occurs, though the donor must receive a replacement heart. This may take place if it is determined that someone with severe lung disease but a healthy heart would have better health outcomes from a combined heart and lung transplant, rather than simply a lung transplant. U.S. Department of Health & Human Services, Organ and Tissue Donation From Living Donors, available at http://organdonor.gov/about/livedonation.html. Live liver, lung, and heart donations, however, are each riskier for the donor than is live kidney donation. The National Kidney Foundation, available at http://www.kidney.org/transplantation/livingdonors/infoqa.cfm#1b.
share of the total, ESRD expenditures grew from 5% in 1991 to 6% in 1999, and have remained at that relative level since then.\(^\text{14}\)

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.\(^\text{15}\) 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 5”), then dialysis or a kidney transplant is required to sustain life.\(^\text{16}\) Typically a dialysis patient spends several hours at a dialysis center three times per week, although there are at-home alternatives. Dialysis can be compatible with a somewhat normal life, but the process imposes rigid structure and limitations of various sorts, and is associated with a variety of medical side effects.\(^\text{17}\) 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.\(^\text{18}\)

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 3,000 patients per year.\(^\text{19}\) But most of the 115,000 new ESRD patients each year are put on dialysis\(^\text{20}\) and at some point may be screened for entry onto the waiting list for a kidney from a deceased donor.\(^\text{21}\) (This waiting list is kept in the United States by the United Network for Organ Sharing, a non-profit organization.) If after extensive testing they are deemed healthy enough to be a candidate for transplantation, they are registered on one or more regional waiting lists.\(^\text{22}\) If they remain relatively healthy and stay 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.\(^\text{23}\) If they do receive a transplant (from either a living or

\(^{14}\) Id. at Figure 11.2.


\(^{17}\) See, for example, Chapter 1 of Daniel Offer, Marjorie Kaiz Offer, and Susan Offer Szafir, Dialysis without Fear. New York: Oxford University Press, 2007.

\(^{18}\) See infra notes ___ and accompanying text (discussing the advantages of transplantation over dialysis).

\(^{19}\) US Renal Data System, Reference Table D.1: Percentages and Counts of ESRD Patients: By Treatment Modality (http://www.usrds.org/reference.aspx, accessed 12/6/13)

\(^{20}\) Id.


\(^{22}\) Id.

\(^{23}\) US Department of Health and Human Services, United States Organ Transplantation: OPTN & SRTR Annual Data Report 2011 p. 19 Tables K1 1.10 and K1 1.11.
deceased donor), their lives are likely to be improved but are still difficult. They must take immunosuppressive drugs, which impair their immune system, and are nonetheless at risk of graft failure. The “half life” of a kidney graft for surviving patients is about 13 years if from a living donor, and 9 years if from a deceased donor. After a transplanted kidney stops functioning (due to graft failure or other reasons), the patient is back on dialysis, and perhaps back on the waiting list. About 14 percent of patients on the UNOS waiting list have undergone a previous kidney transplant. As a group their waiting time tends to be still longer than for first timers because in the process of rejecting their first kidney, they formed anti-human antibodies that make it harder to find compatible future kidney donors.

Figure 1: Number of Transplants in 2012 by Organ

III. The Case for Living Donation

The fact that living kidney donation is available at relatively little risk to the donor suggests that 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 90-days of surgery is 3.1 per 10,000 donors, as compared to .4 per 10,000 in a matched non-donor 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)

25 OPTN & SRTR Annual Data Report 2011, Table K1 6.7 (p. 34).
27 OPTN, Transplants By Donor Type, Based on OPTN data as of September 20, 2013 (data reports on file with law review).
29 Segev et. al, supra note 28 at n. 16. [Note to Law review: no page numbers for the on-line version, so not sure how to pincite).
30 Id.
were $88 thousand for hemodialysis, $72 thousand for peritoneal dialysis, and $33 thousand 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 for living donor-kidneys, which last longer than deceased-donor kidneys. To illustrate, 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 a higher quality of life on several measures, as compared to dialysis, and are more likely to return to work than are dialysis patients. Moreover, living-donor kidneys function longer than deceased- donor kidneys -- about 12-20 years on average, as compared to 8-12 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 are not transplanted until they have been on dialysis for several years. However, time spent on dialysis can negatively affect the 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

31 USRDS 2013 Annual Report at p. [x]. 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, the surgery, and the 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.


34 Id.

35 Id. USRDS reports that:

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.


36 OPTN, Kidney Kaplan-Meier Median Waiting Times For Registrations Listed: 1999 - 2004
Based on OPTN data as of October 11, 2013 (data report on files with law review) (listing median wait times of between 597 and 2030 days, depending on blood type).

37 Herwigg-Ulf Meier-Kriesche and Bruce Kaplan, Waiting Time On Dialysis As The Strongest Modifiable Risk Factor For Renal Transplant Outcomes, 74 (10) TRANSPLANTATION 1377 (2002).
spending some time on dialysis.\textsuperscript{38} One reason is that kidney-related Medicare coverage does not start until the patient is on dialysis, so that even patients who have available a directed donor may not be able to afford the pre-transplant medical workup.\textsuperscript{39}

A recent study attempted to assess the overall effects of increasing the number of living kidney donations.\textsuperscript{40} The thought experiment was to offer a reward to living donors. If that payment increased living donations without changing 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 estimate that if the rate of living donations increased 5\% 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 20\%, the increase would be .39 QALYs per person.\textsuperscript{41}

In sum, dialysis is expensive and results in poor health outcomes for patients, with average life expectancy only 5 years. A successful transplant for patients who are medically eligible is likely to improve their health. The chance of success is greater if the transplant occurs soon after renal failure is established, and no matter when the transplant occurs following renal failure, 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 2,000 waiting for a combination of kidney and pancreas.\textsuperscript{42} The waiting list has increased linearly from about 30,000 in 1995, the first year for which online data are available from UNOS.\textsuperscript{43} The growth is the inevitable result of the fact that the flow of additions to the list has exceeded the flow of removals throughout this period.

\begin{thebibliography}{9}
\item \textsuperscript{38} US Renal Data System
\item \textsuperscript{41} Id.
\item \textsuperscript{42} http://optn.transplant.hrsa.gov/latestData/step2.asp? (accessed Nov. 16, 2013).
\item \textsuperscript{43} OPTN data
\end{thebibliography}
About one-third of those on the waiting list at any one time are not available for an immediate transplant. Most with inactive status are too sick to tolerate a transplant, or have not completed the medical workup for a transplant; among other reasons for being “inactive” are that the patient chooses to postpone the transplant, or is obese, or, in a few cases, is deemed too well. So long as they remain on the waiting list, however, they accumulate “seniority” and gain priority for receiving a transplant when a suitable kidney becomes available.

In Table 1 we document 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 12 months increased by 2,753 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 5,155 of those who were on the waiting list died, and others became too sick.

Table 1: Accounting for flows on and off the kidney waiting list

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. The growing pool of successful transplants also represents a source of demand, since transplants fail in 10 years or so; currently 14 percent of the waiting list consists of patients who have previously received a kidney transplant.

Although the net increase to the kidney waiting list over the course of 2011 was 2,753, that number is not a good measure of the gap between need and supply. 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 in 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 them would actually receive a transplant. In that sense the need for kidneys for transplant is equal to the flow of new additions to the waiting list, or roughly 35,000 at current rates, plus the 3,000 or so who

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44 OPTN & SRTR Annual Data Report 2011, p. 16.
45 Id.
46 Id.
47 Id.

are transplanted before being put on the waiting list. By that definition, there are currently fewer than half as many kidneys for transplant as needed, as illustrated by Figure 2. In other words, the unmet need is on the order of 21,000 kidneys per year.\(^{49}\) The true number may be far higher: we return to this topic in the next section.

Figure 2 provides a historical account of this gap between need and supply.\(^{50}\) That gap appeared when the UNOS data system first went on line in 1995, and has widened over the years since then. Between 1995 and 2006 both flows (new additions and transplants) increased steadily, with the need increasing faster than the supply of kidneys available for transplant. Since 2006 the need has continued to increase each year (albeit more slowly), but the rate of transplants has plateaued.

Figure 2. Kidney waiting list additions and kidney transplants per year, 1995-2012

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 the 65+ age range, with a drop off thereafter. More men than women are transplanted in every age group. Not shown in this diagram is the breakdown by race: African American patients receive about one-quarter of all kidney transplants, which is about twice their share of the US population.\(^{51}\) Yet since ESRD is 3.5 to 5 times as common among black patients than white patients,\(^{52}\) in fact the likelihood of transplant for black ESRD patients is lower than for whites.\(^{53}\)

Fig 3: Kidney Transplants in 2012 by age group and sex of recipient

Table 2 and Figure 4 show the medical conditions leading to entry on to 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 waitlist, from 17,258 in 1995 to 34,834

\(^{49}\) 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 were transplanted before going on dialysis – the most recent count available in 2,855 in 2011. So the relevant comparison is the number of cases newly qualified for a transplant (34,834 + 2,855) with the actual number of transplants (16,485). The difference is 21,204.

\(^{50}\) In fact the gap is even wider than depicted, since as noted above some of the transplants have gone to patients who were never on the waiting list.

\(^{51}\) http://optn.transplant.hrsa.gov/latestData/rptData.asp


in 2012. The number of new entrants with diabetes and hypertension each more than doubled between 1995 and 2012.

Fig 4: medical conditions leading to entry on to the waiting list.

Table 2:

Is it possible to project future need for kidney transplants? 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 medical progress that improves the health of ESRD patients, hence making them better candidates for a transplant, or changes in waitlisting practice), 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.

There is considerable evidence of inconsistency in the process by which some ESRD patients are qualified for the transplant waiting list and others (most) are not. One study found that for patients newly diagnosed with ESRD, many of those not placed on the waiting list were 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 (AHRQ) estimated that an “achievable benchmark” for transplant eligibility was 10 percentage points higher than the current national average. A consistent evidence-based standard applied in every locality could 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

54 K Kalantar-Zadeh. The future of dialysis in the U.S. Renal & Urology News, Oct 1, 2013. This generally stagnant rate of new ESRD patients masks significant differences across age and ethnic groups. For example, in older populations (aged 60+), diabetes rates have declined for African Americans, Native Americans, and Hispanics but have increased for whites aged 70 and older. Id. In the age group 20–39, however, diabetes incidence rates continue to rise for African Americans and Native Americans. Id.


58 Id.
Figure 5 shows trends in kidney donation since 1988. Several trends in Figure 6 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 dotted line in Figure 6, is about twice as high as the number of deceased donors, as most deceased donors yield two transplantable kidneys). Second, the number of deceased donors trended upward from 1988 to 2005, but has plateaued since then, rising only slightly through 2012. In contrast, the number of living kidney donors increased from 1988 to a high in 2003, followed by a decrease through 2012 – surely a matter of concern, but one for which we have no explanation. The net result has been a static trend in overall donations since 2006.

Fig. 5. Trends in kidney donors and kidneys donated from 1988

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 for deceased donation was 18-34, whereas the peak age for living donation was 35-49.

Fig. 6. Kidney donors by age group for 2012, living and deceased

The fact that younger adults have the highest rate of deceased donation is related to the criteria for kidney donation. The medical challenge for the 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 donation specifies a patient who is declared brain dead in a hospital while the heart is still beating, who is aged 60 or less, and who does not suffer from any of a number of medical conditions. (The medical criteria are somewhat looser for patients under age 50.) “Expanded” criteria donors qualify otherwise healthy patients with brain death after age 60, although kidneys from these donors are refused by transplant center about 40% of the time. There are also about one thousand cardiac-death donors each year – patients who are pronounced dead when their heart stops beating, rather than

61 Id. OPTN/UNOS recently approved amendments to OPTN policy that replace the definitions of “standard criteria” and "extended criteria" donors with a Kidney Donor Profile Index (KDPI), a formula designed to classify kidneys based on estimated years of kidney function post-transplant. 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.” U.S. Dept. of Health and Human Services, OPTN/UNOS Board approves significant revisions to deceased donor kidney allocation policy (June 25, 2013), available at http://optn.transplant.hrsa.gov/news/newsDetail.asp?id=1600.
as a result of cessation of brain function – but they too tend to be younger patients who lack co-morbidities.\textsuperscript{62}

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 deaths per 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.\textsuperscript{63} We begin with the fact that almost 2/3 of all deaths are over 70 (and hence almost always deemed medically unacceptable due to age alone). Of the remainder, most are uncontrolled deaths out of the hospital, or deaths in the hospital from causes like cancer, diabetes, and renal disease that ordinarily are disqualifying. In 2010 only about 9,000 deaths were “eligible” by either the standard criteria or expanded criteria, and in 70% of those cases the kidneys were in fact donated. In addition, there were 928 others who became donors after cardiac death, which is uncommon because it is a difficult procedure – once the heart stops beating, the kidneys deteriorate rapidly.\textsuperscript{64} Still, all hospitals which accept Medicare now have DCD protocols, and it is an expanding practice.\textsuperscript{65}

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 currently stands at about 21,000 new cases per year, and is even greater, if any progress is to be made on the backlog.

Table 3: The winnowing process for deceased donors, 2010

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 for the period 1989-1993, most (55%) deceased donors died in a motor vehicle accident, homicide, or other form of head trauma. By 2010 the number of donors who died in motor vehicle accidents had declined somewhat and from homicide had declined to less than half its previous level, though there was considerable growth in the numbers of other donors. The 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:\textsuperscript{66} during that time, the number of motor vehicle deaths declined from 44,000 to

\textsuperscript{62} Citation
\textsuperscript{64} Citation
\textsuperscript{65} Citation
\textsuperscript{66} Kompanje EJO, De Groot YJ, Bakker J. Is organ donation from brain dead donors reaching an inescapable and desirable nadir? Transplantation 2011;91:1177-80
35,000, while the homicide count declined from 27,000 to 17,000. But this “good news” has the unfortunate consequence of reducing one important source of deceased donors.

Fig 7. Causes of death for deceased kidney donors

In sum, the prospect for substantial increases in deceased kidney donation is dim. We lose some suitable donors due to refusal or mismanagement, but the most that could be gained from reducing those losses is about 5,000 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, 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 of us 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.

Fig. 8. Recipient relationship to live donor, 2012

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.

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68 The Iranian model of compensated organ donation has reportedly eliminated waitlists, but created other problems, including a lack of donor follow-up care. See, e.g., Ahad J. Ghods, and Shekoufeh Savaj, Iranian Model of Paid and Regulated Living-Unrelated Kidney Donation, CJASN November 2006 vol. 1 no. 6 1136-1145; Gary S. Becker and Julio Jorge Elias, Introducing Incentives in the Market for Live and Cadaveric Organ Donations, J. Econ. Perspectives, Vol. 21, No. 3 (Summer, 2007), pp. 3-24 (estimating the price at which financial incentives would reduce the kidney waiting list).

69 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”).
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, since at present we can only speculate about consequences.

VII. Conclusion

In this primer, we have provided 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 policymakers are now converging on inducements as a possible solution.

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 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 that 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 point is simply that such efforts are likely to satisfy only about a quarter of current unmet demand.

Living kidney donations will have to make up the rest, leading to our primer’s 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 the fact that there were only 182 nondirected donors in 2012, combined with the recent downward trend in living donations -- despite current education and outreach efforts -- are not encouraging in that regard.

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 cash 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.
Table 1. Accounting for flows on and off the kidney waiting list, 2011

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candidates waiting on 1/1/11</td>
<td>85,082</td>
</tr>
<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>5,155</td>
</tr>
<tr>
<td>Too sick</td>
<td>1,904</td>
</tr>
<tr>
<td>Other removal</td>
<td>3,139</td>
</tr>
<tr>
<td>Candidates waiting on 12/31/11</td>
<td>87,835</td>
</tr>
</tbody>
</table>

Source: United States Organ Transplantation, OPTN & SRTR Annual Data Report, 2011. US DoHHS, Health Resources and Services Administration. Dec. 2012. The statistics in this table combine the data for adult and pediatric cases, and are computed from statistics presented on page 18 (Table K1 1.8) and p. 37 (Table K1 8.5). Patients who are listed, transplanted, and re-listed during the course of 2011 are counted more than once.
Table 2: Kidney waiting list additions by diagnosis, 1995 and 2012

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>1995</th>
<th>2012</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>3,012</td>
<td>7,336</td>
</tr>
<tr>
<td></td>
<td>17%</td>
<td>21%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>4,593</td>
<td>11,201</td>
</tr>
<tr>
<td></td>
<td>27%</td>
<td>32%</td>
</tr>
<tr>
<td>Other</td>
<td>9,653</td>
<td>16,297</td>
</tr>
<tr>
<td></td>
<td>56%</td>
<td>47%</td>
</tr>
<tr>
<td>Total</td>
<td>17,258</td>
<td>34,834</td>
</tr>
<tr>
<td></td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

70 Based on OPTN data as of September 20, 2013: http://optn.transplant.hrsa.gov/latestData/step2.asp?
Table 3. The winnowing process for deceased donors, 2010.

<table>
<thead>
<tr>
<th>Total deaths</th>
<th>2,468,435</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Deaths &gt; age 70</td>
<td>(1,608,440)</td>
</tr>
<tr>
<td>Deaths &lt;= age 70</td>
<td>859,995</td>
</tr>
<tr>
<td>- Deaths out of hospital</td>
<td>(547,123)</td>
</tr>
<tr>
<td>Deaths &lt;= 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>(2,751)</td>
</tr>
</tbody>
</table>

Kidney donors (SCD+ECD) | 6,313 |
+ Recovered kidney donors (DCD) | 928 |
Total kidney donors | 7,241 |

OPO = Standard criteria donor
SCD = Expanded criteria donor
DCD = donation after cardiac death

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)”
d. Table 4.2: Eligible Deaths Reported by U.S. OPOs, 2002-2011. Scientific Registry of Transplant Recipients.

e. Computed as difference between “eligible deaths” and “recovered kidney donors”

f. Table 2.2: Deceased Donor Characteristics, 2002-2011, Kidney Donors. Scientific Registry of Transplant Recipients.

*Includes ICD-10 codes: Certain infectious and parasitic diseases (A00-B99); Malignant neoplasms (C00-C42, C45-C68, C73-C97); Diabetes mellitus (E10-E14); Hypertension with renal insufficiency or renal failure (I12-I15); Renal disease (N00-N29). Based on Ojo et al. (1999). “A Practical Approach to Evaluate the Potential Donor Pool and Trends in Cadaveric Kidney Donation,” Transplantation 67 (4): 548-556.

** From OPTN Glossary: “Although it is recognized that this definition does not include all potential donors, for reporting purposes for DSA performance assessment, an eligible death for organ donation is defined as the death of a patient 70 years old or younger who ultimately is legally declared brain dead according to hospital policy, and: independent of family decision regarding donation or availability of next-of-kin; independent of medical examiner or coroner involvement in the case; independent of local acceptance criteria or transplant center practice; and who exhibits none of the following:

II. Active infections (specific diagnoses) [Exclusions to the Definition of Eligible]:

III. -Bacterial: Tuberculosis; Gangrenous bowel or perforated bowel and/or intra-abdominal sepsis; see sepsis below under General. -Viral: HIV infection by serologic or molecular detection; Rabies; Reactive Hepatitis B Surface Antigen; Retroviral infections including HTLV I/II; Viral Encephalitis or Meningitis; Active Herpes simplex, varicella zoster, or cytomegalovirus viremia or pneumonia; Acute Epstein Barr Virus (mononucleosis); West Nile Virus infection; SARS. -Fungal: Active infection with Cryptococcus, Aspergillus, Histoplasma, Coccidioides; Active candidemia or invasive yeast infection. -Parasites: Active infection with Trypanosoma cruzi (Chagas'), Leishmania, Strongyloides, or Malaria (Plasmodium sp.). - Prion: Creutzfeldt-Jacob Disease.

General [Exclusions to the Definition of Eligible]: -Aplastic Anemia; Agranulocytosis; Extreme Immaturity (<500 grams or gestational age of <32 weeks); Current malignant neoplasms except non-melanoma skin cancers such as basal cell and squamous cell cancer and primary CNS tumors without evident metastatic disease; Previous malignant neoplasms with
current evident metastatic disease; A history of melanoma; Hematologic malignancies - Leukemia, Hodgkin's Disease, Lymphoma, Multiple Myeloma; Multi-system organ failure (MSOF) due to overwhelming sepsis or MSOF without sepsis defined as 3 or more systems in simultaneous failure for a period of 24 hours or more without response to treatment or resuscitation; Active Fungal, Parasitic, Viral, or Bacterial Meningitis or encephalitis.”
Figure 1. Number of transplants in 2012 by organ.\textsuperscript{71}

\textsuperscript{71} Based on OPTN data as of September 20, 2013: http://optn.transplant.hrsa.gov/latestData/step2.asp?
Figure 2. Kidney waiting list additions and kidney transplants per year, 1995 – 2012

Based on OPTN data as of November 15, 2013
http://optn.transplant.hrsa.gov/latestData/rptData.asp
Figure 3. Kidney transplants in 2012 by age group and sex of recipients.
Figure 4. Medical conditions leading to entry onto the kidney waiting list, 1995 and 2012.

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.
Figure 5. Trends in kidney donors and kidneys donated from 1988
Figure 6. Kidney donors by age group for 2012, live and deceased
Figure 7. Causes of death for kidney donors

Head trauma deaths for 2010 include only those not as a result of homicide or motor vehicle accident.

Figure 8. Live donor-recipient relationship, 2012.