Personal Viewpoint

doi: 10.1111/ajt.13813

Financial Neutrality for Living Organ Donors: Reasoning, Rationale, Definitions, and Implementation Strategies

R. Hays¹, J. R. Rodrigue², D. Cohen³, G. Danovitch⁴, A. Matas⁵, J. Schold⁶ and D. LaPointe Rudow⁷,*

In the United States, live organ donation can be a costly and burdensome undertaking for donors. While most donation-related medical expenses are covered, many donors still face lost wages, travel expenses, incidentals, and potential for future insurability problems. Despite widespread consensus that live donors (LD) should not be responsible for the costs associated with donation, little has changed to alleviate financial burdens for LDs in the last decade. To achieve this goal, the transplant community must actively pursue strategies and policies to eliminate unreimbursed out-of-pocket costs to LDs. Costs should be more appropriately distributed across all stakeholders; this will also make live donation possible for people who, in the current system, cannot afford to proceed. We propose the goal of LD "financial neutrality," offer an operational definition to include the coverage/reimbursement of all medical, travel, and lodging costs, along with lost wages, related to the act of donating an organ, and guidance for consideration of medical care coverage, and wage and other expense reimbursement. The intent of this report is to provide a foundation to inform discussion within the transplant community and to advance initiatives for policy and resource allocation.

Abbreviations: ACA, Affordable Care Act; FMLA, Family Medical Leave Act; FN, Financial Neutrality; KPD,

Kidney Paired Donation; LDKT, Live Donor Kidney Transplantation; LD, Live donor; NLDAC, National Living Donor Assistance Center; NOTA, National Organ Transplant Act; OPTN, Organ Procurement and Transplantation Network

Received 09 December 2015, revised 13 March 2016 and accepted for publication 19 March 2016

Introduction

For suitable transplant candidates, a living donor transplant is preferred, providing, on average, longer life and better quality of life than either dialysis or a deceased donor transplant (kidney transplant recipients), and improved access to transplantation for liver transplant candidates whose symptom burdens outweigh Model for End-Stage Liver Disease (MELD) score. Yet in the United States, live liver donation rates account for only 4% of liver transplants (1), and live kidney donation rates have declined over the last decade despite a growing transplant wait list and development of novel methodologies to increase live donor kidney transplantation (LDKT) (e.g. paired exchange, desensitization, ABO-incompatible LDKT, and increased acceptance of nondirected LDs) (2). Although there are many possible reasons for this decline, it coincided with the economic downturn of the mid 2000s: Gill et al and others have posited this may be related to costs to LDs in the United States and the vulnerable socioeconomic status of many potential LDs (3,4).

In the United States, many LDs incur substantial unreimbursed expenses (5). This is in spite of the fact that the National Organ Transplantation Act (NOTA), while outlawing organ donation in exchange for "valuable consideration," specifically stated: "The term 'valuable consideration' does not include 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 ... in connection with the donation of the organ."(6). The concept of reimbursement of LD expenses was reaffirmed in 2004 with the passage of the Organ Donation and Recovery Improvement Act

¹Transplant Center, University of Wisconsin Hospital and Clinics, Madison, WI

²Department of Surgery, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA

³Department of Medicine, Columbia University Medical Center, New York, NY

⁴Department of Medicine, University of California at Los Angeles, Los Angeles, CA

⁵Department of Surgery, University of Minnesota Medical Center-Fairview, Minneapolis, MN

⁶Department of Quantitative Health Sciences, Cleveland Clinic, Cleveland, OH

⁷Recanati Miller Transplantation Institute, Mount Sinai Hospital, New York, NY

^{*}Corresponding author: Dianne LaPointe Rudow, dianne.lapointerudow@mountsinai.org

Hays et al

(P.L. 108-216), which included providing grants for reimbursement of travel expenses incurred by LDs, subject to means testing and linked to a specified recipient. This is now operated under the auspices of the National Living Donor Assistance Center (NLDAC).

There is consensus in the US transplant community that donating should be financially neutral and donationrelated expenses incurred by LDs be reimbursed within the framework of federal law (7-10). Yet despite this agreement, highlighted by a 2006 call to action to limit LD financial disincentives, little has changed over the last decade (11). Clearly, if there is to be movement towards LDs remaining financially whole, or LD "Financial Neutrality" (FN), the transplant community must actively pursue strategies and policies to reach this goal (8). Financial disincentives should not prohibit medically suitable, motivated donors from donating an organ, or result in undue burdens on those who proceed to donate despite such disincentives. However, there is lack of clarity over what FN actually entails. Before strategies can be developed to achieve neutrality, the concept must be defined and operationalized. To this end, we have developed an outline of the principal components of LD FN and provided a starting point in developing strategies to achieve this goal.

In some areas there is a relatively fine line between what might be regarded as LD financial incentives and FN, an issue that is particularly problematic in the United States, a country still lacking universal healthcare access. Even so, we offer more granularity than has been achieved previously, and intend this outline to help structure future discussions for policy initiatives and resource allocation to keep LDs free of financial burden.

Existing Financial Costs of Living Donation and Limits of Available Resources

Evidence suggests that LDs in the United States experience financial hardship throughout the process. Studies report that up to 96% of LDs experienced financial consequences, including 47% with lost wages (12,13). One report showed LDs incurred an average of \$3268 in expenses with some reporting up to \$8000 (12). Financial loss is greater in those who traveled greater distances, had lower household income, and had more unpaid work hours (12). LD expenses range widely because resources to offset costs are variable by state, physical demands of the LD's job (and associated expected recovery time), employer-provided benefits, and ability of the recipient to provide financial assistance (3). In addition, efforts at reducing the financial burdens on LDs remain fragmented and incomplete, leaving many LDs without assistance. Although the NLDAC travel grant has been a valuable resource to some LDs, not all meet eligibility requirements (such as

recipient financial means testing), and fewer than 10% of LDs annually have made use of the travel grant (14). As of this writing, 35 states have implemented tax deductions/credits for live donation expenses, but most require itemization of deductions, which will not assist low-income earners (15). The federal government and some state/local governments offer employees paid leave for recovery from organ donation, but this is not available to most LDs (16).

Furthermore, some potential donor costs are not usually considered when discussing FN, including (1) costs associated with donation-related complications, (2) costs of short- and long-term follow-up for health maintenance or workup of new symptoms thought to be donation-related, and (3) potential for insurability problems after live donation. The Affordable Care Act (ACA) may alleviate health insurability problems (no data available yet), but barriers remain, given the variability in application of ACA adoption and uncertainty about its long-term viability due to legislative and legal challenges. ACA does not address LD problems with life insurability as described in the literature (9,17,18).

The Argument for LD Financial Neutrality

First and foremost, we believe that achieving FN for LDs is the right thing to do. The LD (or potential donor) should not have to pay to be able to donate. Although LDs commonly experience emotional/psychological benefit from helping a loved one, they receive neither health nor economic benefit. In contrast, most transplant recipients receive substantial health benefit from transplantation; transplant centers and professionals increase transplant volume and receive associated academic, financial, and competitive benefits; and society benefits from a smaller transplant wait list and lower healthcare costs when patients transition from endstage disease management to transplantation. As such, from a simple equity standpoint, it is reasonable that the community at large share costs of LD rather than impose them on the LDs alone. This would mirror the system to provide coverage for bone marrow donors in the United States (19).

Second, it is likely that FN would increase LD rates. Financial burdens currently associated with LD may affect potential donor decision-making and ability to proceed. Rodrigue et al noted that approximately two thirds of transplant candidates had concerns about pursuing LDKT because of economic considerations (20). Additionally, transplant candidates and their donors usually have the same socioeconomic status; LDs at most risk for financial burden are often linked with a recipient unable to provide financial assistance (3). Eliminating financial barriers to donation may allow more people to donate.

Financial Neutrality Framework

Building from the language in NOTA, there is logic to defining FN as the coverage/reimbursement of all medical, travel, and lodging costs, along with lost wages, related to the act of donating an organ. To define elements of FN, we identified and discussed expenses that a LD may incur. We concluded that direct and indirect expenses shown in Table 1 constitute key elements of FN. We also determined that there were some expenses that should not be included within the framework of FN (Table 2). We recognize that further discussion within the transplant community and the general public could lead to revisions in these lists.

Direct Medical Expenses

We believe that all direct medical expenses for a potential and actual LD should be covered. Coverage of kidney LD

Table 1: Expenses that should be covered to provide for Live Donor Financial Neutrality: the coverage/reimbursement of all medical, travel, and lodging costs, along with lost wages related to the act of donating an organ

Direct medical expenses

Predonation

- · Pretransplant evaluation
- · Age-appropriate health screening
- · Co-pays/deductibles

Perioperative

- · Inpatient medical care
- Inpatient incidentals
- · Co-pays/deductibles

Postdonation

- · Short-term complications
- · Donation-related follow-up
- · Readmissions
- Workup of new symptoms that may/may not be donation related
- Short-term counseling and long-term psychiatric complications
- · Long-term surgical complications:
- · Long-term disability related to donation
- Miscellaneous outpatient care (e.g. medications, wound care supplies,)
- · Visiting nurse/physical therapy/occupational therapy
- · Co-pays/deductibles
- Coverage of donation-related long-term medical follow-up as determined by the transplant community

Direct nonmedical expenses

Travel costs

Visa

Travel for caregiver

Nondirect expenses

Lost wages

Job insecurity/position reassignment

Dependent care

Vacation used for recovery

College tuition (if donation midsemester)

Higher premiums for health and life insurance

Table 2: Expenses that should not be included in the definition of financial neutrality

Household chores; i.e. housekeeping, gardening, chopping wood, shoveling snow

Passport

Rent/mortgage

Personal care/shopping/other hired chores

Costs for lack of productivity (work and home)

Pain and suffering

Healthy food

Workup of newly diagnosed medical problem predonation

Treatment of preexisting medical condition

direct medical expenses is easily achieved when the recipient is Medicare eligible. Problems occur when the recipient is not Medicare eligible (10-15% of recipients) (2) or when the donor evaluation and/or nephrectomy take place at a different hospital than the transplant (for example, in paired exchange). Certain non-Medicare insurers do not cover any live kidney donor expenses (evaluation, surgery, and complications) including public aid systems in Texas, Oklahoma, and Arkansas. Such variation results in geographic disparities and LD's financial distress. In addition, problems can arise when the potential LD receives testing at a facility outside the transplant program or outside the United States. Coverage for nondirected donors and for those enrolling in Kidney Paired Donation (KPD) are problematic since they are not linked to a specific recipient's insurance until donation. Finally, many insurance plans do not cover live liver donation.

Below is a discussion of the direct expenses we believe should be covered, and mechanisms to resolve gaps in the current system (Table 3).

Predonation evaluation

All LD evaluation expenses including professional fees, laboratory expenses, and diagnostic testing are already covered under Medicare organ acquisition cost reports. However, some LDs incur costs during the evaluation (e.g. for tests at outside facilities) (16). For some, these are not inconsequential and should be covered.

Age-appropriate health screening predonation

There is discussion about whether age-appropriate health screenings (e.g. colonoscopy, mammogram) should be covered as part of the LD evaluation. Some worry that coverage for these tests might be considered as "valuable consideration" if claimed on the organ acquisition cost report (8). We feel that if the transplant program requires testing to make a determination of donor suitability, it should be considered a covered predonation expense.

Gaps in inpatient medical care coverage

The donation hospitalization event is a covered expense with a clear coverage mechanism (i.e. recipient

Table 3: Summary of mechanisms to achieve financial neutrality

Elements of financial neutrality	Process exists	Clarify current policy	Policy change needed	New funding source
Direct medical expenses				
Pretransplant evaluation: professional fees, diagnostic imaging, labs				
Predonation expenses not covered by the recipient				
insurance due to lack of coverage ¹				
Age-appropriate health screening predonation ²				
Inpatient medical care ¹				
Inpatient incidentals (including TV, phone) 3				
Mandated postdonation follow-up including labs ^{1,4}				
Short-term postdonation complications ¹				
Readmissions if suspected to be donation related ^{2,1,4}				
Workup of new symptom postdonation that may or				
may not be donation-related				_
Access to short-term counseling postdonation			/	
Long-term "surgical" complications			/	<i>I</i>
Long-term disability related to donation				
Pain medications/miscellaneous meds supplies (gauze)				
Visiting Nurse/Physical Therapy/Occupational Therapy				
Long-term psychiatric care r/t donation Co-pays/deductibles				
Coverage of routine long-term medical follow-up				1
(professional services and laboratory) as determined by				
the transplant community to be necessitated by live donation				
Direct nonmedical expenses				
Hotel/lodging ⁵	✓ for some			✓
Plane/car/gas/rental/taxi/parking ⁵	✓ for some			1
Food	✓for some			1
Visa costs ⁶	P 101 301110		/	•
Travel insurance				1
Travel for caregiver	✓ for some			/
Nondirect expenses				
Lost wages				/
Job insecurity/position reassignment			/	
Child care/elder care				✓
Vacation used for recovery				✓
College tuition (if donation midsemester) ⁷			✓	
Higher premiums for health and life insurance ⁸				

CMS, Centers for Medicare and Medicaid Services; KPD, kidney paired donation; NLDAC, National Living Donor Assistance Center; NOTA, National Organ Transplant Act.

Medicare). However, there are incidental costs that are not always paid for and may be billed to the donor, such as co-pays, parking, telephone, and meals. We conclude such costs should not be the responsibility of the donor.

Pain medications/miscellaneous medical supplies

Upon discharge the LD may be prescribed medication and require wound care supplies. Costs for these

medications and/or supplies are sometimes incurred by the donor. We recommend these expenses be covered.

Short-term complications

Currently, short-term complications are covered by the recipient's insurance. Occasionally, a LD may need visiting nurse services, physical therapy, or occupational therapy related to the donor surgery; we propose this be

¹Policy: Mandate basic contracting requirements for live donor transplant, with coverage for nondirected donors and donors in KPD regardless of payer.

²Clarification: CMS to clarify appropriate use of the Organ Acquisition Fund with input from transplant community.

³Clarification: Memorandum of clarification from the Department of Justice about what is permissible under NOTA.

⁴Funding: narrowly defined and federally funded donor complication benefit.

⁵Funding: Expansion of NLDAC to cover all donors.

⁶Policy: Define a donation-specific visa designation and to simplify the process at specific embassies.

⁷Policy: Create tuition forgiveness related to donation.

⁸Policy: Create insurability protections.

covered. Additionally, if a complication (e.g. wound infection recurrence or neuropraxia) or hospital readmission occurs after an initial recovery period, and the complication or event is likely related to donation, we recommend that it be covered regardless of time since donation.

Evaluation of new symptoms postdonation

A LD may present to the transplant program with complaints of a new symptom (e.g. pain, numbness, or digestion changes) not present predonation and inquire if this is donation related. The cost to evaluate the symptom (e.g. professional fees, diagnostic testing, labs), and to make a determination whether its etiology is donation related, should be covered, regardless of time since donation. Problems can occur in the context of KPD, in which the center where the LD gets care may have different standards than the center receiving the kidney.

Mental health services

Although most LDs report satisfaction with donation and no lasting adverse impact on quality of life, (21–23), some have psychological complications necessitating treatment postdonation (24–28). We conclude that mental health evaluation at the LD's facility of choice should be covered to determine whether psychological or psychiatric symptoms are related to donation, along with appropriate mental health treatment (e.g. counseling, psychopharmacology) if symptoms are related to donation. More controversial are LDs who present with mental health symptoms long after donation. Again, however, if suspected or proven to be donation related, care should be covered regardless of the location of service or time since donation.

Long-term surgical complications

Some LDs have surgical complications (e.g. incisional hernia, small bowel obstruction) that may occur months to years after donation (29). Again, if these are determined to be most likely donation related, they should be covered.

Ultimately, the donor team should determine what a donation-related complication is and be able to offer care accordingly. If the LD disagrees with the determination of the transplant team, an independent group should be available to arbitrate. A mechanism for the creation of such a review board is needed. One proposal could be the creation of a review board through the Organ Procurement and Transplantation Network (OPTN) since they have expertise and experience with review boards.

OPTN-mandated postdonation follow-up

Currently, the OPTN requires that all LD transplant programs report accurate and timely clinical and laboratory follow-up data for 1 year following live liver donation, and for 2 years following live kidney donation (30). No LD

should be responsible for costs associated with clinical follow-up and laboratory tests required by the OPTN for donor tracking.

Long-term health maintenance

Related to individual health practices and lack of universal healthcare, the long-term health maintenance varies from donor to donor. In light of recent data suggesting a small increase in end-stage renal disease after kidney donation, the transplant community needs to discuss and support the need for access to long-term medical follow-up of LDs. Specifics are discussed in the Controversies section (31–35).

Direct Nonmedical Expenses

Direct nonmedical expenses comprise incidentals related to accessing care, and getting to the transplant center. In contrast to direct medical expenses, there is no national system of reimbursement for most LDs, given the limited NLDAC eligibility requirements. LDs currently pay travel costs (airfare/gas/rental/taxi/parking; hotel or lodging; food; and travel insurance) for themselves and potentially a caregiver (9,16). LDs who come from overseas may also incur visa costs. Our group concluded these expenses should be covered.

Indirect Expenses

Indirect expenses for LDs refer to the LDs recovery time and its impact on the LD and their caregiver's work, activities, and support, as well as LDs future insurability concerns. Our group believes that employment and wage impact should be minimized. LDs should not be in jeopardy of job loss or position reassignment. Not all LDs' jobs are eligible for Family Medical Leave Act (FMLA) protections, and at times, employers have excluded LD recovery from FMLA (9). We contend that LDs should not have to use vacation time (a form of wage) for the purpose of donation. LD lost wages should be covered, though the principle of "financial neutrality" has some practical limitations. For example, it is unrealistic to expect all salaries to be completely covered since some donors may earn significantly more than a fund can support. However, most very high salaried individuals are likely to continue to be paid while out of work for a few weeks and lose no income from donating. We propose that federal wage reimbursement with a ceiling of coverage, similar to programs already in place in Canada and Australia, should be available to all LDs.

For LDs receiving unemployment compensation, we proposed an eligibility extension to cover time lost during donation recovery. Similarly, if a transplant is scheduled midsemester, we believe that a student LD should receive tuition reimbursement (or forgiveness). Likewise,

Hays et al

incidentals (e.g. dependent care) during donation recovery should be covered to a reasonable ceiling amount via a federal system. In addition, we agree that LDs should not be faced with difficulties acquiring health or life insurance, nor should they pay increased premiums as a result of being a LD.

Long-term disability related to donation

In extremely rare cases a LD has a serious adverse event resulting in permanent disability. To preclude severe financial loss for the LD, we conclude there should be a safety net for these few unfortunate LDs. We suggest that all LDs be provided narrowly defined disability insurance to reduce long-term financial sequelae resulting from donation.

Controversies

Although the concept of FN was easy to endorse, we had spirited discussion about how this could be translated into practice, given the vagaries of the US healthcare system, employment law, and the complexities of defining, many years after the event, what health sequelae might be "donation-related." We struggled to identify all medical issues to include in covered diagnoses; in principle, any additional costs of care as a result of donation should be included. We agreed, for example: if a pregnant past LD is considered to have a high-risk pregnancy (36) and is advised to have additional appointments and blood pressure monitoring, this should be covered; if preeclampsia occurs and is thought to be donation related, treatment for it should be covered. Examples of other medical issues we propose should be covered include exacerbation of preexisting medical conditions, progressive chronic kidney disease, surgical complications, and depression if determined to be donation-related.

More complex but rare complications include issues that result from the surgical procedure that require ongoing medical treatment. For instance, if a LD suffered a myocardial infarction in the perioperative period, immediate treatment should be covered but at what point does it not become donation related? If a catheterization or surgery is indicated? Should medications be covered indefinitely? Specific areas of discussion in which consensus was not attained within our authorship group include whether earlier-onset cardiac disease for a past LD should be covered or if new-onset hypertension after donation could be attributed to donation. Although there may exist an incremental risk of chronic kidney disease, hypertension, or other conditions after kidney donation, it is very difficult in any single individual to reliably attribute the occurrence of these conditions to the donation. Importantly, as discussed above, if new evidence supports the need for additional long-term monitoring or care, these costs should be covered. We recognize that defining donation-related complications is a complex problem and not easily resolved. We recommend that guidelines be created by a multidisciplinary task force to include transplant clinicians, primary care physicians, payers, and LDs, with recommendations to include an annotated list of complications potentially eligible for coverage. Important aspects to consider include discussion of whether recommendations should vary based on individual LD risk factors (age, ethnicity, comorbidities).

In an effort to increase live donation rates, various forms of financial incentives for LDs have been proposed (37–39). These ideas should be clearly distinguished from our proposal. Achieving FN aims to improve the donation experience for LDs, though it is anticipated that in doing so, more LDs (particularly those of limited financial means) will be able to donate.

Next Steps

Designing and implementing systems to achieve financial neutrality for LDs is a major endeavor, made more complicated by variability in LD cost burden, limited reliable data, intricacies of NOTA interpretation, lack of a national system of tax and employment protections, lack of national healthcare, a controversial healthcare reform law, and Congressional budget restrictions. In general, we believe that reaching FN for LDs will be achieved through five broadly defined approaches (Table 4). These should be public policy priorities. They are discussed individually below.

Improved Guidance and Intertransplant Center Cooperation

Currently, some LDs are charged for incidentals. These are directly related to the donation event. We believe these costs should be covered by all transplant centers. Ideally, Centers for Medicare and Medicaid Services

Table 4: Specific elements to address to achieve LD financial neutrality

Steps to achieve financial neutrality in living donation

- 1 Issuance by the Federal Government of a National Guidance Document:
 - a Clarification of what individual transplant centers can cover without being in violation of NOTA
 - b Improved guidance regarding the Organ Acquisition Cost Report
- 2 Contracting guidelines for private insurance coverage
- 3 Policy initiatives to offer LDs civil protections
- 4 Resource allocation to develop systems for wage reimbursement and coverage of LD medical needs long-term

LD, live donor; NOTA, National Organ Transplant Act.

(CMS) could clarify whether or not they can be submitted to the Organ Cost Acquisition account.

We encourage seeking a memorandum for clarification from the Department of Justice about what is permissible under NOTA, and that "reasonable payments" include all direct and incidental costs of the donor hospitalization associated with the recovery. There has been a precedent for this in relation to KPD in 2007 (40). Both can be achieved with the creation of a federally issued National Guidance Document to standardize the process.

Improved guidance in utilization of the Organ Acquisition Report will clarify coverage for LD routine health maintenance screening during the evaluation phase, coverage of postoperative complication, and other aspects of follow-up. All insurance carriers covering solid organ transplantation should be required to cover live donation costs at least according to the Medicare regulations. Until such policy is developed, we conclude that all transplant hospitals should ensure that contracts with payers include adequate coverage for the LD. Education of and cooperation between hospitals, billing departments, and insurance carriers need to be improved to prevent errors in billing. In addition, standardization of coverage to facilitate KPD is warranted.

Policy and Legislative Initiatives to Offer LDs Protections

Risk of job loss or reassignment, and problems with insurability after donation, can only be addressed with policy and legislative improvements. Specifically, we support the Live Donor Protection Act recently introduced in Congress bicamerally (H.R. 4616/S. 2584) in 2016 (41). This proposal would limit insurability impact for LDs and would specify that FMLA protections apply in the context of live donation.

We recommend policy changes to ensure that LD medical costs are adequately covered. All public and private payers should cover LD care for each insured policyholder meeting criteria for transplantation. This includes evaluation expenses for all potential donors, and for those proceeding to donation, the expenses related to surgery and follow-up. Policies should also be amended to mandate that payers cover evaluation of symptoms suspected to be related to the donation.

In practice, achieving FN for living donors may require simultaneous revision of reimbursement policies from payer organizations in order to address the concern of adverse selection (i.e. potential recipients might prefer insurance contracts with living donor reimbursement benefits). As such, coordinated discussions with payers may be a critical step to implement policy reform.

New Resource Allocation to Address Lost Wages

We encourage learning from LD wage reimbursement systems already implemented around the world, including Canada, the Netherlands, Australia, and Israel, and 19 countries in the European Union (5,42–44). We acknowledge that LD financial burdens were simpler to consider in many of these countries, which have universal job protections and systems of nationalized healthcare. That said, the majority of LD-specific, new programs were built with mechanisms to provide wage reimbursement during donation recovery, and in some cases also offer reimbursement of incidentals (e.g. childcare). The individual countries' programs vary in implementation, but could inform US policy and systems design.

For the United States, we propose expansion of the already-existing NLDAC program to cover all LDs (by eliminating the means test and by eliminating the requirement to link an application with a specific recipient) and to offer a standardized system for wage reimbursement. Dollarfor-dollar wage reimbursement is impractical to propose, and instead we suggest modeling other countries' systems, which offer reimbursement-with-a-ceiling. In the current federal budgetary environment, expansion of any existing programs must either be cost neutral or offset by additional revenues. Since every LD transplant represents a cost savings to the federal government, a strong argument could be made that achieving FN for LDs will pay for itself through increased rates of live donation. Frankly, even if it doesn't pay for itself, ethically it is the right thing to do; the people shouldering the medical risks of an unnecessary surgery should not also shoulder the costs. This justifies why we recommend that federal governmental changes assume responsibility for achieving FN.

New Resource Allocation to Cover Costs of LD Medical Follow-Up

In order to cover long-term costs associated with routine postdonation follow-up, as well as the rare-but-problematic long-term medical complications resulting from donation, new funding sources will be required. We endorse the concept of a narrowly defined federal benefit for past LDs to cover donation-related medical costs. As a small modification, we also suggest that to reduce travel costs for past LDs, coverage should allow LDs to access care at their provider of choice.

Conclusions

Although the notion of FN for LDs in the United States is not controversial, its components have not previously been clearly articulated. We have defined FN as the coverage of expenses related to organ donation, including

Hays et al

lost wages, medical costs, and travel costs. We have offered detail in these definitions, particularly regarding medical costs that LDs are responsible for currently. We present for discussion ways to achieve FN within the current legal framework. We urge an immediate concerted effort to clarify current allowances and implement new funding sources and policies so that the cost of live donation is not a barrier and so LDs themselves don't bear these burdens. Achieving FN for LDs should be a public policy priority for all stakeholders. A national conference including transplant professionals, representatives of CMS, Health Resources and Services Administration, local governments, payers, and LDs should be convened to address FN for LDs.

Disclosure

The authors of this manuscript have conflicts of interest to disclose as described by the *American Journal of Transplantation*. Jesse Schold is on the Board of Directors of the American Society of Transplantation. The other authors have no conflicts of interest to disclose.

References

- Organ Procurement and Transplantation Network. 2016 [cited Jan 25, 2016]. Available from: https://optn.transplant.hrsa. gov/converge/data/.
- Matas AJ, Smith JM, Skeans MA, et al. OPTN/SRTR 2013 Annual Data Report: Kidney. Am J Transplant 2015; 15(Suppl 2): 1–34
- Gill JS, Gill J, Barnieh L, et al. Income of living kidney donors and the income difference between living kidney donors and their recipients in the United States. Am J Transplant 2012; 12: 3111–3118.
- Rodrigue JR, Schold JD, Mandelbrot DA. The decline in living kidney donation in the United States: Random variation or cause for concern? Transplantation 2013; 96: 767–773.
- Sickand M, Cuerden MS, Klarenbach SW, et al. Reimbursing live organ donors for incurred non-medical expenses: A global perspective on policies and programs. Am J Transplant 2009; 9: 2825–2836.
- National Transplant Act 1984 [cited 2015 Nov 20]. Available from: https://history.nih.gov/research/downloads/PL98-507.pdf.
- Living Kidney Donor Follow-Up Conference Writing G, Leichtman A, Abecassis M, et al. Living kidney donor follow-up: Stateof-the-art and future directions, conference summary and recommendations. Am J Transplant 2011; 11: 2561–2568.
- LaPointe Rudow D, Hays R, Baliga P, et al. Consensus conference on best practices in live kidney donation: Recommendations to optimize education, access, and care. Am J Transplant 2015; 15: 914–922.
- Tushla L, Rudow DL, Milton J, Rodrigue JR, Schold JD, Hays R. Living-donor kidney transplantation: Reducing financial barriers to live kidney donation—Recommendations from a consensus conference. Clin J Am Soc Nephrol 2015; 10: 1696–1702.
- Delmonico FL, Martin D, Dominguez-Gil B, et al. Living and deceased organ donation should be financially neutral acts. Am J Transplant 2015; 15: 1187–1191.

- Gaston RS, Danovitch GM, Epstein RA, Kahn JP, Matas AJ, Schnitzler MA. Limiting financial disincentives in live organ donation: A rational solution to the kidney shortage. Am J Transplant 2006; 6: 2548–2555.
- Klarenbach S, Gill JS, Knoll G, et al. Economic consequences incurred by living kidney donors: A Canadian multi-center prospective study. Am J Transplant 2014; 14: 916–922.
- Rodrigue JR, Schold JD, Morrissey P, et al. Direct and indirect costs following living kidney donation: Findings from the KDOC study. Am J Transplant 2016; 16: 869–876.
- Warren PH, Gifford KA, Hong BA, Merion RM, Ojo AO. Development of the National Living Donor Assistance Center: Reducing financial disincentives to living organ donation. Prog Transplant 2014; 24: 76–81.
- Lacetera N, Macis M, Stith SS. Removing financial barriers to organ and bone marrow donation: The effect of leave and tax legislation in the U.S. J Health Econ 2014; 33: 43–56.
- Rodrigue JR, Schold JD, Morrissey P, et al. Predonation direct and indirect costs incurred by adults who donated a kidney: Findings from the KDOC study. Am J Transplant 2015; 15: 2387–2393.
- Jacobs CL, Gross CR, Messersmith EE, et al. Emotional and financial experiences of kidney donors over the past 50 years: The RELIVE study. Clin J Am Soc Nephrol 2015; 10: 2221–2231.
- Boyarsky BJ, Massie AB, Alejo JL, et al. Experiences obtaining insurance after live kidney donation. Am J Transplant 2014; 14: 2168–2172.
- Be the Match; National Marrow Donor Program 2016 [cited 2016 Mar 18]. Available from: https://bethematch.org/supportthe-cause/donate-bone-marrow/donation-fags/.
- Rodrigue JR, Cornell DL, Kaplan B, Howard RJ. Patients' willingness to talk to others about living kidney donation. Prog Transplant 2008; 18: 25–31.
- Jin SG, Xiang B, Yan LN, et al. Quality of life and psychological outcome of donors after living donor liver transplantation. World J Gastroenterol 2012; 18: 182–187.
- Clemens KK, Thiessen-Philbrook H, Parikh CR, et al. Psychosocial health of living kidney donors: A systematic review. Am J Transplant 2006; 6: 2965–2977.
- Clemens K, Boudville N, Dew MA, et al. The long-term quality of life of living kidney donors: A multicenter cohort study. Am J Transplant 2011; 11: 463–469.
- Dew MA, Myaskovsky L, Steel JL, DiMartini AF. Managing the psychosocial and financial consequences of living donation. Curr Transplant Rep 2014; 1: 24–34.
- Jowsey SG, Jacobs C, Gross CR, et al. Emotional well-being of living kidney donors: Findings from the RELIVE Study. Am J Transplant 2014; 14: 2535–2544.
- Lentine KL, Schnitzler MA, Xiao H, et al. Depression diagnoses after living kidney donation: Linking U.S. Registry data and administrative claims. Transplantation 2012; 94: 77–83.
- Ladner DP, Dew MA, Forney S, et al. Long-term quality of life after liver donation in the adult to adult living donor liver transplantation cohort study (A2ALL). J Hepatol 2015; 62: 346–353.
- 28. Humphreville VR, Radosevich DM, Humar A, et al. Long-term health-related quality of life after living liver donation. Liver Transpl 2016; 22: 53–62.
- Abecassis MM, Fisher RA, Olthoff KM, et al. Complications of living donor hepatic lobectomy—A comprehensive report. Am J Transplant 2012; 12: 1208–1217.
- Organ Procurement and Transplantation Network (OPTN). Policies of the OPTN; Policy 18: Data Submission Requirements.

Financial Neutrality for Living Organ Donors

- [cited 2016 Mar 19]. Available from: http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Policies.pdf#nameddest=Policy_18.
- Muzaale AD, Massie AB, Wang MC, et al. Risk of end-stage renal disease following live kidney donation. JAMA 2014; 311: 579–586.
- 32. Mjoen G, Hallan S, Hartmann A, et al. Long-term risks for kidney donors. Kidney Int 2014; 86: 162–167.
- Steiner RW. 'Normal for now' or 'at future risk': A double standard for selecting young and older living kidney donors. Am J Transplant 2010; 10: 737–741.
- Steiner RW, Ix JH, Rifkin DE, Gert B. Estimating risks of de novo kidney diseases after living kidney donation. Am J Transplant 2014; 14: 538–544.
- Lentine KL, Schnitzler MA, Xiao H, et al. Racial variation in medical outcomes among living kidney donors. N Engl J Med 2010; 363: 724–732.
- Garg AX, McArthur E, Lentine KL; Donor Nephrectomy Outcomes Research N. Gestational hypertension and preeclampsia in living kidney donors. N Engl J Med 2015; 372: 1469–1470.
- 37. Salomon DR, Langnas AN, Reed AI, et al. AST/ASTS workshop on increasing organ donation in the United States: Creating an "arc of change" from removing disincentives to testing incentives. Am J Transplant 2015; 15: 1173–1179.

- 38. Satel S. Why people don't donate their kidneys. 2014 [cited 2014 May 4]. Available from: http://www.nytimes.com/2014/05/04/opinion/Sunday/why-people-dont-donate-their-kidneys.html? $_r = 0$.
- Newell KA, Formica RN, Gill JS. Engaging living kidney donors in a new paradigm of postdonation care. Am J Transplant 2016; 16: 29–32
- U.S. Department of Justice Memorandum for Daniel Meron General Counsel, Department of Health and Human Services; Re: legality of alternative organ donor practices. 2007 [cited 2016 Mar 19]. Available from: https://web.stanford.edu/~alroth/ JusticeDeptMemo.KidneyExchange.March2007.pdf.
- The Live Donor Protection Act: H.R. 4616/S. 2584 2016 [cited 2016 Mar 7]. Available from: https://www.govtrack.us/ congress/bills/114/hr4616?utm_campaign=govtrack_feed&utm_ source=govtrack/feed&utm_medium=rss.
- Australian donor costs reimbursement program. 2016 [cited 2016 Mar 19]. Available from: www.humanservices.gov.au/ leaveforlivingorgandonors.
- 43. Canadian donor costs reimbursement program. [cited 2016 Mar 19]. Available from: http://www.kidney.ca/bc/loderp.
- 44. Israeli donor costs reimbursement program (in Hebrew). [cited 2015 Oct 24]. Available from: http://www.justice.gov.il/NR/rdon lyres/F8E6E7B8-D67A-475A-B64A-F9B86797F282/9952/2144.pdf.