

## Living Donor Kidney Transplantation: Improving Education Outside of Transplant Centers about Live Donor Transplantation—Recommendations from a Consensus Conference

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### Abstract

Living donor kidney transplantation (LDKT) offers better quality of life and clinical outcomes, including patient survival, compared with remaining on dialysis or receiving a deceased donor kidney transplant. Although LDKT education within transplant centers for both potential recipients and living donors is very important, outreach and education to kidney patients in settings other than transplant centers and to the general public is also critical to increase access to this highly beneficial treatment. In June 2014, the American Society of Transplantation's Live Donor Community of Practice, with the support of 10 additional sponsors, convened a consensus conference to determine best practices in LDKT, including a workgroup focused on developing a set of recommendations for optimizing outreach and LDKT education outside of transplant centers. Members of this workgroup performed a structured literature review, conducted teleconference meetings, and met in person at the 2-day conference. Their efforts resulted in consensus around the following recommendations. First, preemptive transplantation should be promoted through increased LDKT education by primary care physicians and community nephrologists. Second, dialysis providers should be trained to educate their own patients about LDKT and deceased donor kidney transplantation. Third, partnerships between community organizations, organ procurement organizations, religious organizations, and transplant centers should be fostered to support transplantation. Fourth, use of technology should be improved or expanded to better educate kidney patients and their support networks. Fifth, LDKT education and outreach should be improved for kidney patients in rural areas. Finally, a consensus-driven, evidence-based public message about LDKT should be developed. Discussion of the effect and potential for implementation around each recommendation is featured, particularly regarding reducing racial and socioeconomic disparities in access to LDKT. To accomplish these recommendations, the entire community of professionals and organizations serving kidney patients must work collaboratively toward ensuring accurate, comprehensive, and up-to-date LDKT education for all patients, thereby reducing barriers to LDKT access and increasing LDKT rates.

*Clin J Am Soc Nephrol* 10: 1659–1669, 2015. doi: 10.2215/CJN.00950115

### Introduction

For patients with ESRD who are eligible for transplantation, live donor kidney transplantation (LDKT) offers better quality of life and clinical outcomes, including patient survival (1,2), compared with remaining on dialysis or receiving a deceased donor kidney transplant. Providing comprehensive education to patients about the benefits of LDKT as early as possible can increase the chances that patients with kidney failure will fully explore the option of LDKT, reach out to living donors, and ultimately receive a LDKT (3,4).

Although education about LDKT within transplant centers for both potential recipients and living donors is very important (4), outreach and education to kidney patients in settings other than transplant centers and to the general public is also needed, for several reasons. First, when patients are in the earlier stages

of CKD (stages 3 or 4), conversations with primary care physicians (PCPs) and community nephrologists about the benefits of a preemptive LDKT may lead to initiation of a transplant evaluation and facilitate the possibility for some to avoid dialysis altogether and receive a LDKT (5,6). Second, because 73% of patients with ESRD receive regular in-center dialysis treatments in approximately 6000 centers in the United States (1), systematized education within this setting can provide a much needed opportunity to educate more patients with ESRD about LDKT, including those who have not yet presented to a transplant center for evaluation. Third, ensuring that comprehensive LDKT education occurs within dialysis centers may help to reduce known ethnic or racial disparities in access to transplant education (7,8) and LDKT (9) by teaching these patients about their option for LDKT and about the steps needed to begin evaluation

Due to the number of contributing authors, the affiliations are provided in the Supplemental Material.

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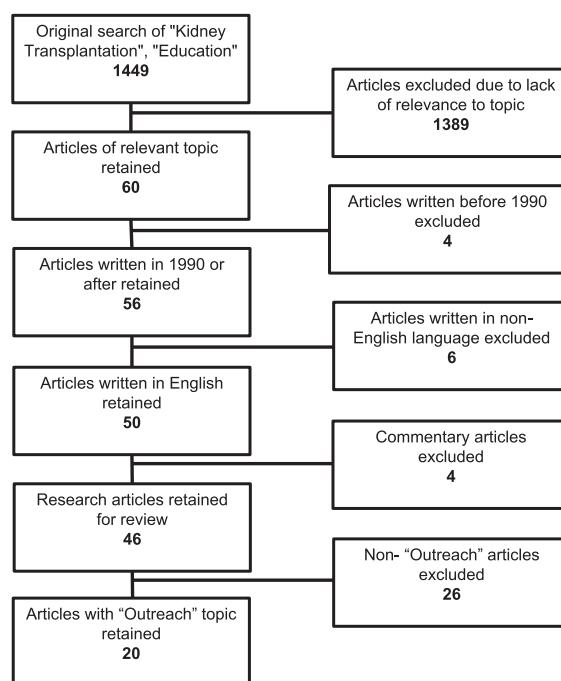
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or seek living donors. Fourth, although positive messages about donating kidneys upon death are available to the general public (10), misinformation about LDKT still remains and can be exacerbated by inaccurate media portrayals (11). Finally, public awareness and education about LDKT is also needed to educate potential living donors and kidney patients in learning about the risks and benefits of LDKT so that they make informed decisions.

### Consensus Conference Workgroup on Best Practices in LDKT Educational Outreach

Initiated by the American Society of Transplantation's Live Donor Community of Practice and cosponsored by 10 additional societies, a consensus conference on best practices in live kidney donation was conducted in Rosemont, Illinois, in June 2014. Five workgroups convened to identify and disseminate best practices for educating transplant and donor candidates about LDKT and living donation, improving efficiencies in the living donor evaluation, and reducing disparities and systemic barriers in LDKT and living donation. High-priority recommendations from this conference have been reported elsewhere (12). These recommendations include (1) adopting an approach that LDKT is the best treatment option for eligible patients, (2) repeating of LDKT education through the course of a kidney patient's disease progression for patients who are eligible, (3) supporting transplant and dialysis providers and staff members to improve their ability to educate patients on the risks and benefits of LDKT and their approaches to helping transplant candidates effectively and ethically engage potential donors, (4) improving educational content about LDKT across transplant centers, and (5) creating a LDKT financial toolkit.

One of the five workgroups at the consensus conference focused on identifying best practice strategies for educating transplant candidates about LDKT in settings outside of a transplant center and for educating the general public. The workgroup was composed of 14 transplant professionals (authors of this manuscript; Supplemental Material), including three transplant professionals with psychology backgrounds, four with nursing backgrounds, six physicians with nephrology backgrounds, and one social worker. All individuals currently work in transplant settings, with most having conducted research about transplantation and living donation. The transplant outreach workgroup conducted a structured literature review in PubMed to determine LDKT educational strategies with evidence of success and others that showed promise for future exploration. In total, 46 articles on general transplant education topics (*e.g.*, educational strategies applied within a transplant center for patients pursuing transplantation) were identified and reviewed, with 20 of these being directly relevant to strategies that might reach patients before they come to the transplant center (Figure 1). This article supplements the original literature search with other supporting research, especially articles from non-transplant-related fields. During the five conference calls and the in-person meeting, the workgroup members reviewed the articles, discussed known transplant outreach practices and barriers to success, and reached consensus on what else was needed to increase referrals to transplant



**Figure 1. | Results of the structured literature review on kidney transplantation educational strategies.**

centers and best inform transplant candidates about the option of LDKT.

This article describes the relevant literature and the six main recommendations that emerged. Although kidney patients, their family members and friends, and any potential living donors should all be comprehensively educated about LDKT, the recommendations discussed within this article focus on optimal LDKT education of the kidney patient before he or she ever presents to a transplant center as well as education of the general public at large.

### Need for Improved LDKT Education Outside of Transplant Centers

Although comprehensive transplant education is a concept open to interpretation, a few studies have suggested key components that should be included. The US Centers for Medicare and Medicaid Services' (CMS) mandate for dialysis patients to be informed of their options, which was rolled out in the CMS Conditions for Coverage (13), establishes the minimum that dialysis providers must advise patients of their transplant option. However, additional content elements to ensure that patients can make informed decisions are currently undefined in regulatory guidance (14). Comprehensive education would address both the benefits and risks of deceased and living donor transplantation compared with each other, dialysis, and no treatment (15). Furthermore, quantitative and qualitative work with potential and past kidney recipients about their needs for education (16,17) recommended that educational material should address the following: (1) practical issues around the evaluation process and surgery for both recipients and donors; (2) common concerns about LDKT, including those about harm and inconvenience to donors; and (3) ways donors

may benefit from LDKT. From a provider’s perspective, dialysis nephrologists have indicated the importance of spending adequate time with each patient (>20 minutes) to review benefits, risks, practical issues, and concerns and to answer questions (18). Finally, comprehensive education would, if the patient desired, help overcome logistical barriers to pursuing transplantation, such as contacting the transplant center (19). Although this definition of “comprehensive education” is not necessarily exhaustive, it provides a general scope for reference in this article.

Because it involves performing a medical procedure on an otherwise healthy individual, the practice of LDKT has required a clearly articulated ethical justification, often based on the benefits of expected positive outcomes for the LDKT recipient and minimal, well characterized risks to donors (20,21). Although a full review of the ethical issues implicated in LDKT is beyond the scope of this article, educational outreach for LDKT must not lead to coercion of potential donors and should increase access for both the recipient and donor to information that helps them fully understand the benefits and risks of LDKT and living kidney donation (22). The consensus conference membership has taken care not to recommend any outreach strategies that would promote pressuring potential donors, but it instead advocates for increasing the availability of information about LDKT so that patients with ESRD and their family members and friends can consider whether it is an appropriate treatment option.

Optimally, comprehensive education of kidney patients about LDKT should be occurring at all stages of a patient’s CKD to ESRD trajectory. These stages include: before the CKD diagnosis, where a person may become generally exposed to transplantation and LDKT through public information campaigns; at the point of diagnosis of more advanced renal dysfunction, when the patient begins to interact more frequently with PCPs, community nephrologists, or dialysis providers; through the patient’s arrival at the transplant center to begin evaluation; and afterward, when the patient is wait-listed, seeks a compatible living donor, or considers the option of paired donation. Figure 2 demonstrates these stages, highlighting key potential opportunities for LDKT education along the continuum.

Not all patients are equally likely to receive education about transplantation and LDKT at early stages of CKD or ESRD diagnoses. Compared with white patients, minority kidney patients are less likely to receive transplant education before presenting for evaluation and they often begin evaluation less knowledgeable or ready to pursue transplantation (23). Black, Hispanic, and Asian patients are also less likely to receive LDKTs than white patients. Although 23% of the transplants received by whites in 2014 were LDKTs, 12%, 19%, and 19% of the transplants received by blacks, Hispanics, and Asians, respectively, were LDKTs (based on Organ Procurement and Transplantation Network data as of March 13, 2015). Because patients who present to a transplant center less prepared to pursue transplantation are less likely to ultimately receive LDKTs (23), previous recommendations for reducing racial disparities in LDKT include education and interaction with patients before they reach ESRD and immediately after they begin dialysis, as

well as dissemination of education about LDKT to the general public (24).

### Recommendations of the Transplant Outreach and Education Workgroup

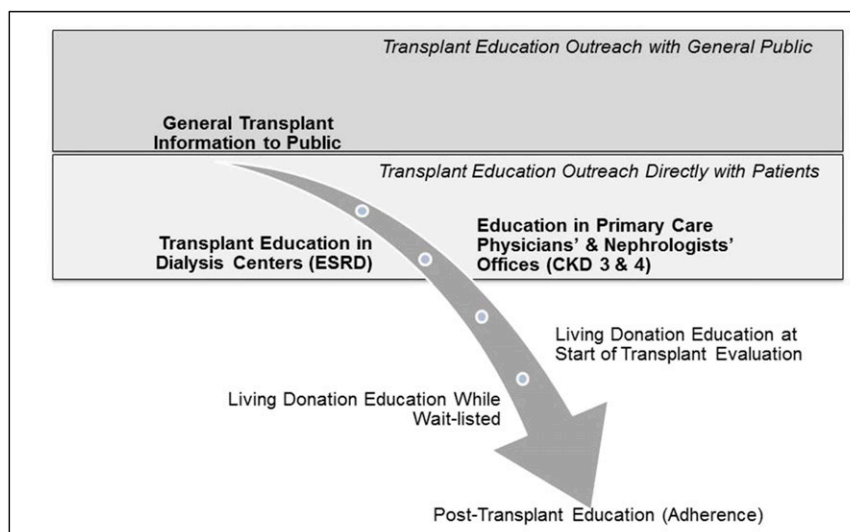
This workgroup generated six recommendations for improving transplant outreach and education outside of transplant centers (Table 1). These recommendations include efforts to promote preemptive transplantation, support dialysis providers to educate their patients about LDKT, foster partnerships between various transplant and community organizations, increase the use of technological developments in outreach efforts, place a greater emphasis on providing transplant education in rural areas, and develop a public message about LDKT. These recommendations are discussed in detail below.

#### Preemptive Transplantation Should Be Promoted through Increased LDKT Education by PCPs and Community Nephrologists

Patients with stages 3–4 CKD who have reduced but residual kidney function are commonly seeing community nephrologists to make dietary and medication changes to slow or prevent progression of their kidney disease and to explore their RRT options (25). This is the optimal time to discuss the possibility of preemptive LDKT, with its survival benefits compared with receiving LDKT or a deceased donor kidney transplant after starting dialysis (6,26). After a review of the literature on educational outreach, the first workgroup recommendation was to increase preemptive LDKT education by PCPs and community nephrologists (27), with a focus on key disadvantaged populations (24,28).

The National Kidney Foundation’s (NKF) Kidney Early Evaluation Program (29) and others (30) found that pre-dialysis education significantly increases the number of preemptive transplant wait-listings and LDKTs.

<b>Table 1. Workgroup key recommendations</b>	
Recommendations	
<ul style="list-style-type: none"> <li>● Preemptive transplantation should be promoted through increased LDKT education by primary care physicians and community nephrologists</li> <li>● Dialysis providers should be trained to educate their own patients about DDKT and LDKT</li> <li>● Partnerships between community organizations, organ procurement organizations, religious organizations, and transplant centers should be fostered to support transplantation</li> <li>● Use of technology should be improved or expanded to better educate kidney patients and their support networks</li> <li>● LDKT education and outreach should be improved for kidney patients in rural areas</li> <li>● A consensus-driven, evidence-based public message about LDKT should be developed</li> </ul>	
<p>LDKT, living donor kidney transplantation; DDKT, deceased donor kidney transplantation.</p>	



**Figure 2.** | Continuum of transplant education highlighting key touch points for outreach.

Community nephrologists are ideal providers to educate about preemptive LDKT to help motivated patients avoid dialysis entirely and help patients unsure about transplantation learn more about it and take the most appropriate next steps. The National Kidney Disease Education Program, established in 2000 by the National Institute of Diabetes and Digestive and Kidney Diseases, provides information for patients at risk for kidney disease as well as for people who already have it, including information on LDKT (31). One study documented that nephrologists were seven times more likely to inform patients of their transplant options if the patient had seen the nephrologist for >3 months, illustrating that trust and a deepening relationship between the provider and the patient with CKD was a foundation for this important discussion (32). With limited time by physicians to discuss transplant options in detail with each individual patient, LDKT discussions may be further enhanced by additional education by other providers within these practices. For example, a randomized controlled trial focused on increasing preemptive LDKT among patients in community nephrologists' practices compared the effect of a social worker–led intervention, a print and video educational intervention, and the standard-of-care education from community nephrologists (33). Boulware *et al.* (33) found that patients receiving the social worker and educational interventions were more likely to have discussions about LDKT with their physicians and to complete transplant evaluation within 6 months. Because these services may not be readily available in most practices, comprehensive, accurate, and up-to-date online electronic resources and printed materials could be developed and disseminated.

Some community providers, particularly PCPs or providers within the first few years of working with kidney patients (34), may need an orientation on the most important LDKT-related educational content and messages to share with patients with stages 3–4 CKD and their families, particularly on the benefits of preemptive transplantation. An available curriculum of focused talks, trainings, and access to relevant journal articles guiding providers

through the LDKT educational process and orienting them toward improvements in the field should be developed to help guide community providers. Continuing medical education credits could be given for participation in this curriculum.

There is also evidence that patients rely on PCPs to help them access additional, specialized medical care (35) and that coordination of specialized care through a PCP is associated with higher trust in one's medical providers (36). Racial and ethnic minorities, who are more likely to rely only on a PCP for medical care, and others without a community nephrologist may also benefit from receiving education about kidney disease, kidney failure, and their transplant options directly from their PCPs (28). To our knowledge, although there has been discussion of ways PCPs can support their patients with kidney disease by helping them move on to transplantation (37), there are no published studies about transplant educational interventions utilizing PCPs to date. Trials could be designed and implemented to test and develop best practices in this area.

### **Dialysis Providers Should Be Trained to Educate Their Own Patients About LDKT and Deceased Donor Kidney Transplantation**

Some patients may not be aware that they have kidney problems until they present in an emergency room with ESRD (38). Racial and ethnic minorities are more likely to present with ESRD requiring immediate dialysis (1). Others have such a fast decline in their kidney function that they do not have time to learn about preemptive LDKT. For these patients, LDKT education should begin as soon as it is practical after dialysis initiation.

Unfortunately, barriers to receiving transplant education within dialysis centers are high and include some providers' lack of training in transplantation, insufficient patient educational resources, difficulty staying current with new scientific developments about LDKT and paired exchange programs, and perceived lack of time to educate about LDKT (18,39). Thus, the workgroup recommended that a



process be developed to ensure that transplant and dialysis team members attain competency in understanding the benefits and risks of LDKT, methods for communicating risks and benefits, and ways to provide guidance to transplant candidates on effective and noncoercive approaches to engaging potential donors. Dialysis centers are currently mandated by the CMS to inform their patients of the option for transplantation within the first 45 days of dialysis initiation (13). Although dialysis centers report rates of compliance to the CMS around informing new patients about transplantation to be as high as 70%–80% (14,40), patients themselves report lower rates (64%) of their providers initiating transplant discussions (14).

The quality and comprehensiveness of the transplant education that dialysis patients receive is also unknown. Waterman *et al.* (39) found that dialysis administrators (*e.g.*, nurse managers) had low knowledge of transplantation and were only able to answer approximately 50% of questions about transplantation correctly, and they reported that their staff members were not trained to educate about transplantation and did not have enough time to educate their patients; there was also high agreement by these administrators (93%) that their dialysis providers needed to be better educated about transplantation themselves. Balhara *et al.* (18) found that, on average, dialysis providers reported spending  $\leq 20$  minutes educating their patients about transplantation, a less ideal amount of time that was associated with a lower likelihood of using comprehensive educational practices such as one-on-one sessions, repeated discussions, and involvement of family members. One efficacious transplant education practice at the dialysis center includes the use of patient navigators; Sullivan *et al.* (19) found that compared with a standard-of-care education control group, patients randomized to receive the guidance of a patient navigator took significantly more steps toward attending and completing transplant evaluation, with a higher proportion of patient-navigated patients on the waitlist for a transplant than control patients.

To overcome these barriers, training sessions led by transplant experts designed to improve dialysis providers' transplant knowledge and capacity to educate their own patients about LDKT and provide them with education to disseminate to their own patients may be helpful (41). Further research must determine to what extent this type of training is needed and how it can be most effective. Partnering dialysis providers with a transplant outreach coordinator who can answer LDKT questions, support transplant referrals, and even conduct education directly with dialysis patients and their family members or friends can also be helpful. In addition, the use of educational resources such as Living ACTS (About Choices in Transplantation and Sharing), which has been shown to increase patients' willingness to talk to the families about LDKT (42), could be an effective way to support dialysis providers in educating their patients. Transplant education certification and online training courses may also be useful in helping dialysis providers gain competency in provision of transplant education. Finally, researchers and other experts specializing in transplant education should give talks and publish articles about the value of LDKT in professional and academic print media commonly read by dialysis leadership.

Policy-level changes may also contribute to improving transplant education in dialysis centers. Although dialysis

staff members have a CMS mandate to inform their patients of the option of transplantation once within the first 45 days of dialysis initiation as one of their treatment options (13), inconsistencies in the transplant education provided to patients remain in what is actually occurring in the >6000 United States dialysis centers (18,40). Thus, the workgroup recommends that, in partnership with dialysis leadership, standards be established to clearly define what constitutes sufficient transplant education for dialysis patients, including specific educational content about LDKT that must be covered by the dialysis provider. The workgroup also recommends that there be a methodology developed for monitoring and documenting compliance with these standards, whether by CMS or other appropriate regulatory agencies.

### **Partnerships between Community Organizations, Organ Procurement Organizations, Religious Organizations and Transplant Centers Should Be Fostered to Support Transplantation**

Kidney professionals are not the only people who have knowledge about treatments for kidney failure, and transplant and dialysis centers are not the only places to receive LDKT education. To better educate patients about LDKT, the workgroup also recommends that partnerships between kidney care providers and other stakeholders, including national and local community organizations, nonprofit organizations, organ procurement organizations, and religious organizations, be strengthened. Table 2 lists many of these stakeholder organizations.

Because some community nephrologists, PCPs, and dialysis providers may have limited awareness of, or access to, LDKT educational resources or the knowledge of the best approaches to administer this education, the workgroup recommended that kidney organizations assist healthcare providers by providing greater access to LDKT education resources for their patients and offering training in using these resources. Education should be provided in multiple languages, written in plain language at no more than a sixth- to seventh-grade level (43), and offered in DVD or online format, if possible. Making LDKT information accessible to patients and potential donors of low health literacy can be considered an ethical obligation, because they must be able to fully understand the processes implied and expected outcomes of LDKT to fully give consent (22). Several programs with demonstrated efficacy in increasing successful referrals for transplantation and pursuit of LDKT (41,44) could be recommended. Education about alternative living donor programs such as paired exchange and desensitization should also be provided for patients who have avoided presenting for transplantation because they do not realize that LDKT is possible with incompatible donors (*e.g.*, <http://www.kidneyregistry.org>, <http://www.paireddonation.org>, or <http://www.unos.org/donation/index.php?topic=kpd>).

In addition to supporting community providers in educating their own patients, organizations such as a CKD-based pharmacy clinic (45), a state kidney organization's patient education program (46), and other nonprofit organizations, including the American Association of Kidney Patients (47) and the NKF (48), interact with and provide education for patients directly as they progress through the different stages of CKD and ESRD and make their transplant decisions (45). The NKF also has a program entitled NKF Peers

**Table 2. Transplant- and kidney-focused organizations with LDKT resources**

Organization	Website	Description
<b>Kidney disease and treatment options</b>		
American Association of Kidney Patients	<a href="http://www.aakp.org">http://www.aakp.org</a>	Provides advocacy, education, and interaction for kidney patients
Coalition on Donation	<a href="http://www.organtransplants.org/donor/coalition/">http://www.organtransplants.org/donor/coalition/</a>	Manages and promotes donation, develops and executes effective multimedia donor education programs, and motivates the American public to register now as organ, eye, and tissue donors
Explore Transplant	<a href="http://www.ExploreTransplant.org">http://www.ExploreTransplant.org</a>	Supports patients and kidney care providers with educational programs and training seminars
Kidney School	<a href="http://kidneyschool.org/">http://kidneyschool.org/</a>	Features educational models for patients and providers about kidney disease and its treatments
Living Donors Online	<a href="http://www.livingdonorsonline.org">http://www.livingdonorsonline.org</a>	Provides an online network for living donors (including potential donors) and their families providing education, support, and advocacy
National Kidney Foundation	<a href="http://www.kidney.org">http://www.kidney.org</a>	Provides information for patients, medical professionals, and the public
PKD Foundation	<a href="http://www.pkdcure.org">http://www.pkdcure.org</a>	Offers comprehensive information about polycystic kidney disease and its treatment options
Renal Support Network	<a href="http://www.rsnhope.org">http://www.rsnhope.org</a>	Provides nonmedical services to those affected by CKD, including education about transplantation
Renewal	<a href="http://www.life-renewal.org/home">http://www.life-renewal.org/home</a>	Provides education, referrals, and logistical support to Jewish patients seeking and receiving living donor transplantation or living donors
Transplant Living	<a href="http://www.transplantliving.org">http://www.transplantliving.org</a>	Offers information about living donation and supporting patients throughout the process
Transplant Recipients International Organization	<a href="http://www.trioweb.org/">http://www.trioweb.org/</a>	Provides education about transplantation in general, as well as financial issues around transplantation
US Department of Health and Human Services	<a href="http://www.organdonor.gov">http://www.organdonor.gov</a>	Provides comprehensive information about organ donation and transplantation
<b>Locating a transplant center</b>		
Organ Procurement and Transplantation Network	<a href="http://optn.transplant.hrsa.gov">http://optn.transplant.hrsa.gov</a>	Provides a member directory that allows patients to search for nearby transplant centers
<b>Financial assistance with transplant</b>		
American Kidney Fund	<a href="http://www.kidneyfund.org">http://www.kidneyfund.org</a>	Educates patients about financial support for treatment, medication, and surgery costs
American Transplant Foundation	<a href="http://www.americantransplantfoundation.org">http://www.americantransplantfoundation.org</a>	Financially assists with lost wages after surgery and lack of access to essential medications
HelpHOPELive	<a href="https://m.helphopelive.org/supportfortransplant">https://m.helphopelive.org/supportfortransplant</a>	Supports patients in fundraising campaigns to help cover medical costs of transplantation; raises awareness about transplantation
Kidney Transplant/Dialysis Association	<a href="http://www.ktda.org/">http://www.ktda.org/</a>	Provides financial aid, education, and social activities for kidney patients and donors

Table 2. (Continued)		
Organization	Website	Description
National Foundation for Transplants	<a href="http://www.transplants.org">http://www.transplants.org</a>	Assists transplant candidates and recipients in raising money for costs not covered by insurance
National Living Donor Assistance Center	<a href="http://www.livingdonorassistance.org">http://www.livingdonorassistance.org</a>	Provides financial assistance with travel costs and expenses associated with living organ donation
<b>Provides education about alternative LDKT options</b>		
Alliance for Paired Donation	<a href="http://www.paireddonation.org">http://www.paireddonation.org</a>	Links transplant candidates with matching potential living donors and provides education about paired donation
Living Donation California	<a href="http://livingdonationcalifornia.org/living-donors-are-needed/">http://livingdonationcalifornia.org/living-donors-are-needed/</a>	Educates about the need for living donation and the living donation process, especially for motivated individuals who do not have a specified recipient
National Kidney Registry	<a href="http://www.kidneyregistry.org/">http://www.kidneyregistry.org/</a>	Links transplant candidates with matching potential living donors and provides education about paired donation
United Network for Organ Sharing	<a href="http://www.unos.org/donation/index.php?topic=kpd">http://www.unos.org/donation/index.php?topic=kpd</a>	Provides information about kidney paired donation and about the United Network for Organ Sharing’s Kidney Paired Donation Pilot Program

LDKT, living donor kidney transplantation.

(49), which is a national, telephone-based peer support program in which patients who are newly diagnosed with CKD, are new to dialysis, are considering transplantation, or have received a transplant can connect with a mentor who has already been through the same experience. There are even some preliminary programs wherein dialysis patients educate each other about transplantation, although more research on their effectiveness is still needed (50,51).

Finally, some national and community organizations have also established programs that provide financial assistance to reduce supplementary costs for eligible transplant candidates and reimbursements for living donors associated with kidney donation, including those associated with evaluation, donor nephrectomy, and hospitalization after surgery (52–54). With research showing that patients of lower socioeconomic status may be less likely to receive LDKTs (55), access to these types of services for themselves or their potential donors may make the difference between patients receiving the benefits of LDKTs or remaining on long-term dialysis. This evidence has led to recent arguments to make living donation financially neutral so that donors do not incur substantial costs in the process (56,57). As such, the workgroup recommended that information about these programs be available at the point of first contact for all potential transplant candidates and potential living donors (e.g., in community nephrology, dialysis, and primary care offices).

**Use of Technology Should Be Improved or Expanded to Better Educate Kidney Patients and Their Support Networks**

Increasing LDKT outreach implies an increased responsibility for PCPs, dialysis providers, and staff members, as

well as community nephrologists, who may already face large caseloads and have little time to provide education (18,39,58). This accentuates the need for technology-driven educational solutions (e.g., web-based resources, smart phone-based education) that allow for comprehensive education to be provided while minimizing the burden on providers’ time. Many transplant centers and kidney organizations have also developed LDKT educational websites, including online forums for both potential recipients (<http://www.trioweb.org>) and living donors (<http://www.livingdonorsonline.org>) to ask questions. Trisolini *et al.* (59) recommended expansion of the Dialysis Facility Compare website so that it provides (1) more ESRD information, including information regarding transplant options, for predialysis patients and their caregivers and (2) education resources for predialysis providers to use with their patients. Whether through Dialysis Facility Compare or other government-based educational resources (e.g., the National Kidney Disease Education Program) and non-governmental web-based transplant education resources (e.g., <http://www.kidneyschool.org>, <http://www.transplantliving.org>, or <http://www.exploretransplant.org>), the availability of standardized online education, based on content approved by leading transplant organizations, may be a promising way to increase outreach with LDKT education. Such a resource would also reduce redundancy, because transplant programs could link to this resource rather than invest time and resources into building proprietary education. Indeed, one of the recommendations of the consensus conference includes establishing a national educational website for patients and the general public as

well as developing a financial toolkit for living kidney donors, both of which could be supported by the American Society of Transplantation.

The New Jersey Transplant Surgeon Designee Program, developed 25 years ago to foster communication between dialysis units and transplant centers in New Jersey, teaches dialysis nurses how to help their patients achieve transplantation. Education includes basic information on how to refer patients and kidney allocation, and emphasis is also placed on living donation, alternative programs in living donation, and current trends in transplantation (60). In New Jersey, each dialysis unit is required to have a least one transplant designee on staff and the designees obtain either new or renewed certification through a yearly education program conducted by a New Jersey transplant center. Over the years, because of its popularity, the education program has added tracks for social workers and dietitians, with typical attendance of 400 professionals each year.

The Living Donation California initiative has piloted a website with the aim of helping prospective donors and interested family members and friends learn more about nondirected living donation (<http://livingdonationcalifornia.org/living-donors-are-needed/>). The site's integration of education components, eligibility self-assessment, and referral processes represents one of the more advanced LDKT online resources available. Use of other technologies, including mobile health applications such as transplant education on mobile phones (61), coordinated communication through social media networks (e.g., Facebook) (62), and educational message texting initiatives, can also be used to educate kidney patients, their friends and family members, and potential living donors.

#### **LDKT Education and Outreach Should Be Improved for Kidney Patients in Rural Areas**

Patients living in rural areas and smaller towns have lower wait-listing and transplantation rates than those in urban areas (63). With transplant centers predominately located in more urban areas, exposure to the advantages of transplantation may be lower for rural patients. Furthermore, racial disparities for black dialysis patients living in rural areas may be exacerbated, with rural blacks even less likely than urban blacks to receive transplants (64).

In reviewing the education outreach literature, we found examples of rural outreach programs (65–69) and strategies to engage rural communities (70,71). Harward (65) described the University of North Carolina Kidney Center's Kidney Education Outreach Program, which targets counties in North Carolina with a high prevalence of ESRD and provides screenings and educational and medical information to share with PCPs. The program also helps identify health-care resources for underserved people. Jennette *et al.* (70) used focus groups in a 2010 study, in which 200 residents of rural areas with high ESRD prevalence suggested that television be used as a medium for promoting screenings and awareness of CKD. The residents also felt that the best places to engage community members were in churches or Walmart stores. These types of sites could also be used as venues to engage patients with CKD in LDKT education during the course of screening and awareness campaigns.

In addition, transplant and dialysis centers may want to develop specific quality improvement efforts related to

LDKT education and referral targeted to their rural patients. Because they reside further from dialysis units as well, rural patients may exhibit a greater incentive to obtain a transplant if they are able to learn about it as an option. Some transplant centers are establishing outreach clinics to reduce the burden of transplant evaluation for interested patients by providing onsite medical testing and education in rural locations or in cities several hours away from their centers (70). Nonprofit dialysis organizations, which more commonly serve rural patients (64,72,73), may have the infrastructure and patient contact to widely disseminate LDKT education among patients outside of urban areas. Because screening and outreach programs require additional resources to implement and evaluate, partnerships between kidney and transplant organizations already providing outreach (see Table 2), researchers, dialysis organizations, and transplant centers should be fostered to examine how outreach can be conducted efficiently within already existing organizational capacities.

#### **A Consensus-Driven, Evidence-Based Public Message About LDKT Should Be Developed**

Coordinated national and state-based campaigns to increase deceased donor designation—such as documentation of an individual's decision to donate organs, eyes, and/or tissues after death, either on a driver's license or through a state donor registry (74)—were very effective, with the number of designated deceased donors increasing from approximately 60 million in 2006 to nearly 120 million in 2014 (75). As a result, 43% of organs recovered from deceased donors nationwide were authorized by donor registries (75). To support the campaign, a transplant professional society workgroup, the Donor Designation Collaborative, agreed to utilize a research-tested public message about donor designation, "You Have the Power to Donate Life," to create consistency across state lines. Although California and Vermont have begun LDKT educational campaigns either online or through the Department of Motor Vehicles, there has not been a similar national public campaign aiming to increase awareness of LDKT and recommending that interested kidney patients and potential living donors learn more about it. This lack of a national campaign is attributable to variation in living donor evaluation and candidacy processes, as well as ethical concerns about the need for living donors to approach decision-making without any risk of pressure or coercion. Public education that promotes the facts around the risks and benefits of LDKT could ethically raise awareness while dispelling myths the public may have.

The proven success of previous public education campaigns in numerous applications from antismoking efforts (76) to increased participation in the organ donation registry (77) demonstrates the potential of such a coordinated campaign for LDKT. However, because of the remaining ethical dilemmas around LDKT and living kidney donation and the imperative that nephrology and transplant providers be able to provide unbiased living donor evaluation and support, public messages about living donation would need to be crafted carefully and with consensus from a broad range of stakeholders with potentially divergent opinions about LDKT and living donation. As a first step, the workgroup recommended convening a diverse



range of stakeholders, including healthcare representatives, researchers, community organizations, transplant candidates, and living donors to discuss possible content of a clear, motivating, and medically accurate public message about LDKT. One key decision would be how, and to what extent, public LDKT education should include family members and friends of transplant candidates. Attention to the cultural competency of any public campaign is also important, including but not limited to adapting and translating public LDKT messages into other languages, representing patients (*e.g.*, images, example stories) of various races and ethnicities in educational materials, incorporating concepts and perspectives shown to be important to various racial and ethnic groups, and addressing concerns of various racial and ethnic groups. Finally, it is also important that both the benefits and the risks of LDKT be addressed in these messages.

The workgroup also emphasized the importance of governmental support in championing an approved public message about LDKT. Government backing of a message that LDKT is a good treatment for some patients with ESRD may help transplant programs, dialysis providers, community nephrologists, PCPs, and other CKD stakeholders align to introduce and promote LDKT. Increased opportunities from governmental agencies funding research are also recommended to provide support for research studies on how a national public campaign about LDKT could be informatively and ethically executed and monitored for impact.

If LDKT education for kidney patients only occurs in transplant centers, patients who do not present for evaluation will have less access to the information they need to make an informed decision about how best to treat their ESRD. To ensure that comprehensive LDKT education is received by all eligible patients, the workgroup on transplant outreach emphasized the importance of starting the LDKT education process as early as possible to increase the likelihood that patients with CKD begin thinking about LDKT, discussing the possibility of LDKT with family and friends, and, ideally, locating a willing living donor (78). They also recommend developing targeted LDKT education interventions for groups less likely to receive LDKTs, particularly patients who are ethnic or racial minorities, socioeconomically disadvantaged, or living in rural areas. In general, LDKT education of patients with advanced stages of CKD should be repeated and should occur at multiple points throughout the disease progression and transplant evaluation processes. LDKT education should be occurring by an entire network of PCPs, community nephrologists, dialysis and transplant providers, and community organizations serving kidney patients. A limitation of this consensus conference was not including the views of PCPs, dialysis leaders, patients, or members of the general public; more research with these parties must be conducted to generate a more complete view of outreach strategies that may likely succeed. Whenever possible, state-of-the-art social media, mobile health applications, and other computerized technologies should be utilized to expand the LDKT educational reach to the largest group of patients, family members, friends, and potential living donors interested in learning more. Finally, the field as a whole should align behind a consensus-driven, evidence-based public message about LDKT and should develop educational interventions consistent with this

message. Only then can we ensure comprehensive LDKT education for all patients, reduce barriers to LDKT access, and increase LDKT rates.

Although these recommendations have some support from transplant literature or from other related fields, there is also still a need for well controlled studies at the patient, provider, and system levels to test the effectiveness of these recommended outreach approaches. Important outcomes to be measured include improvements in patients' LDKT knowledge and in rates of transplant referrals, living donor evaluations, and LDKT. Additional research on whether targeted LDKT education outreach interventions work equally well for racial/ethnic minorities and low-income patients is also important, with special attention placed on overcoming barriers to LDKT that are particularly affecting these populations. Evidence from such studies will provide additional guidance and elucidate the next steps for improving educational outreach to allow more patients with ESRD to benefit from LDKT.

#### Acknowledgments

We acknowledge the sponsors of the consensus conference, including the American Foundation for Donation and Transplantation, the American Kidney Fund, the American Society of Transplantation, the American Society of Nephrology, the American Society of Transplant Surgeons, the American Transplant Foundation, Interlink, NATCO, the NKF, the Transplantation Society, and the United Network for Organ Sharing.

Preparation of this manuscript was supported by the National Institutes of Health National Center for Advancing Translational Science (Grant UL1-TR000124 to A.D.W.) and the National Institute of Diabetes and Digestive and Kidney Diseases (Awards R01-DK079665 and R01-DK085185 to J.R.R.).

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Diabetes and Digestive and Kidney Diseases or the National Institutes of Health.

#### Disclosures

A.D.W. is the founder of the nonprofit organization Explore Transplant, where she has provided a royalty-free agreement to the nonprofit to sell education and training to any organization or individual who may benefit from these materials and services. She does not have any financial affiliation with the organization.

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Published online ahead of print. Publication date available at [www.cjasn.org](http://www.cjasn.org).

This article contains supplemental material online at <http://cjasn.asnjournals.org/lookup/suppl/doi:10.2215/CJN.00950115/-/DCSupplemental>.