The Kidney Transplant Collaborative (KTC) is a 501(c)(4) nonprofit organization dedicated to increasing kidney transplants and removing financial and logistical barriers for kidney patients, donors, and their families. Unlike other initiatives, KTC is specifically focused on increasing the number of living donor transplants in the United States through policy advocacy, education, and community organizing. For more details, visit www.kidneytransplantcollaborative.com.

CONGRESSIONAL BRIEFING – THE LIVING VOLUNTEER ENGAGEMENT (LOVE) ACT

Proposal: Congress Can Enact the LOVE ACT To Establish a Living Donation Facilitator Program for Advanced Chronic Kidney Disease Patients and Potential Living Donors, Enhancing Existing Medicare Policy and Saving Billions of Dollars.

A recent private study, using Congressional Budget Office scoring conventions, has estimated that each kidney transplant saves the Medicare program $800,000 over ten years.[1] Doubling the number of living donor transplants over the next decade would reduce Medicare spending by $6.6 billion.

Overview

Americans with End Stage Kidney Disease (ESKD) have two options: dialysis, which is an expensive and difficult treatment, or a kidney transplant. Yet, there is a significant shortage in America of kidneys available for transplant. While kidneys are available for transplant from both deceased and living donors, the available number of deceased donor kidneys will not meet the need, and xenotransplantation (from animals, likely genetically modified pigs) and bio-artificial kidneys will likely not be available for widespread clinical use until 10 years at the earliest. There are many more kidneys available from potential living donors and tens of thousands of living Americans would be willing to donate a kidney. To date, however, Medicare has not leveraged its statutory and regulatory authority to expand living kidney donation.

An estimated 21,000 deceased donors and 6,000 living donors donate a kidney each year. But the kidney transplant waitlist includes nearly 100,000 Americans. While the number of deceased donors has increased 250% over the past 20 years, the number of living donors has not increased at all.

[1] The Moran Company, The Living Organ Volunteer Engagement (LOVE) Act: Fiscal Implications (March 15, 2024), available from author.

Recent modeling published in JAMA Network Open underscores the urgency of expanding both deceased and living donation. The study estimated that to maintain current waiting times, approximately 2,800 additional kidneys would be required under a 10% waitlist expansion and more than 11,000 under a 50% expansion. This clearly demonstrates that reductions in nonuse rates alone are insufficient and that increased living donation must be part of the solution.[2]

Notably, Medicare already spends substantial sums covering the complex process of decreased organ recovery, ranging from donor testing and organ preservation to procurement and even high cost deceased organ transportation, such as private jet transfers that can exceed tens of thousands of dollars per case. The use of private jets to transport kidneys for transplant has spawned an entire cottage industry of jet companies.[3] [4] By comparison, recognizing the modest costs associated with living donor facilitators would require only a fraction of that investment. Incorporating these facilitator expenses into the Organ Acquisition Cost framework would be a logical and efficient extension of existing Medicare policy, ensuring that relatively small expenditures translate into far greater numbers of successful transplants and lives saved.

Congress can enact legislation to make living donation more possible for recipients and donors alike – both to improve health outcomes and to reduce Medicare spending. More specifically, Congress could clearly establish living donor transplant facilitation as a transplant hospital reimbursable activity. This update would create specific trainers to teach and support living kidney transplant facilitators to assist recipients in identifying living donors and support living donors in getting through the transplant process. The legislation would allow the expense of the facilitators to be reimbursed as a reasonable cost on the transplant hospital cost report. Through these specific actions to increase the number of living donors, thousands of lives and billions of Medicare dollars could be saved.

The Opportunity

Congress has a remarkable opportunity to build on significant executive action to modernize kidney transplant regulation and increase living donation. Congress could enact legislation clarifying existing regulation in legislation that would, for the first time, advance living donation across the nation.

More specifically, Congress could amend the living donor provisions of the Medicare statute to create a specialized Living Kidney Transplant Facilitator program for ESKD and advanced CKD patients who are potential transplant recipients and for the prospective living donors who are prepared to help them. The legislation would allow transplant programs to provide training services to allow families and friends to serve as navigators for the potential recipient, and to assist potential living donors in getting through the transplant process. By clarifying that these activities would be deemed reasonable costs

[2] JAMANetworkOpen.2025;8(3):e251665.doi:10.1001/jamanetworkopen.2025.1665

[3] https://www.blade.com/The-Role-of-Air-Transport-in-Kidney-Transplants

[4] https://www.transmedics.com/national-ocs-program/

eligible for reimbursement through the hospital cost report, transplant programs could hire qualified transplant facilitators to assist individuals helping both recipients and living donors through the program, increasing the number of living donor transplants, improving health outcomes, and saving the Medicare program significant sums.

A more detailed explanation of the issue and the proposed solution follows:

The Problem

Almost One Million Americans Have Kidney Disease: The National Institutes of Health reports that as of March 2025 about 833,000 Americans were living with End-Stage Kidney Disease (ESKD).[5] There are two primary treatments for the disease – dialysis or kidney transplant. As of March 31, 2025, 516,837 Americans are on dialysis. As of October 2025, over 93,000 patients are on the kidney transplant waitlist. With only 27,000 transplants occurring in 2024, the waitlist is growing faster than the number of individuals receiving a transplant. Sadly, the United States now ranks 22nd in the world in transplants for people on dialysis.[6]

Medicare Spending on Kidney Disease Is Very High and Rising: Medicare spends a massive amount to treat ESKD patients on dialysis. The National Kidney Foundation reports that Medicare each year spends more than $130 billion (24% of overall spending) on patients with kidney disease and ESKD, which affects 1% of Medicare beneficiaries and accounts for 7% of total Medicare spend.[7] Similarly, the NIH estimates that in 2021, 13.5% of the approximately 23.9 million Medicare fee for service beneficiaries over 66 years old years had a diagnosis of Chronic Kidney Disease (which includes ESKD), accounting for nearly one-quarter (24.1%) of total Medicare spending – an estimated $76.8 billion dollars. Within that group, approximately two thirds of the cost ($52.3B in 2021) was spent on care for ESKD beneficiaries.

Kidney Transplant Is the Optimal Treatment – Both from a Health and Fiscal Perspective: Kidney transplant is the "optimal treatment" for those facing or on dialysis. "Although not a cure for kidney disease, a transplant can help a person live longer and improve quality of life. On average, patients experience 14 to 16 years of function from a kidney from a living kidney donor, while few people survive more than a decade on dialysis."[8] The health benefits of transplant are further enhanced by the cost savings. A recent private study, using Congressional Budget Office scoring conventions, has estimated that each kidney

[5] https://www.niddk.nih.gov/health-information/health-statistics/kidneydisease#:~:text=End%2Dstage%20Kidney%20Disease%20(ESKD),-According%20to%20the&text=More%20than%20808%2C000%20people%20in,to%20develop%20ESKD%20than%20females.

[6] https://usrds-adr.niddk.nih.gov/2023/end-stage-renal-disease/11-internationalcomparisons#:~:text=Finland%20(139%20per%20thousand)%2C,2021%20(Figure%2011.17b).

[7] https://www.kidney.org/get-involved/advocate/legislative-priorities/federal-investment

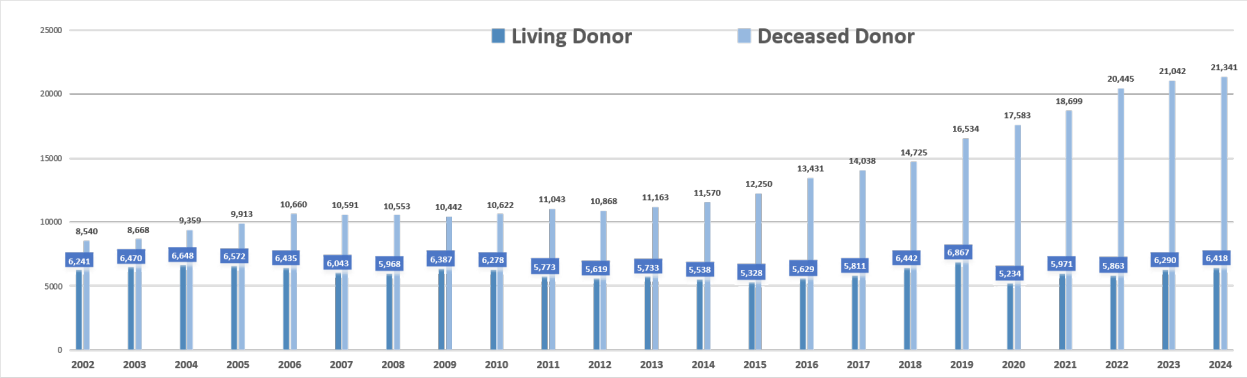
[8] Medicare Program; Alternative Payment Model Updates and the Increasing Organ Transplant Access (IOTA) Model, 89 Fed. Reg. 96280, 96294 (December 4, 2024).

transplant saves the Medicare program $800,000 over ten years.[9] Doubling the number of new living donor transplants over the next decade would reduce Medicare spending by $6.6 billion.

Deceased Donor Kidneys are Rising but Living Donor Rates Are Stagnant: There are two sources for kidney transplants: kidneys donated by deceased donors, and those donated by living donors. Living donor organs are preferable for two reasons: (1) there will never be sufficient deceased organs available to meet patient needs;[10] and (2) living donor kidneys last nearly twice as long as deceased donor kidneys,[11] producing far better recipient health outcomes and avoiding individuals returning to the waitlist for a second transplant.

Living donation also creates the best opportunity for a preemptive kidney transplant. Preemptive transplants are associated with the highest survival rates, improves quality of life and significant cost savings by avoiding the high expenses of the months immediately before and after dialysis initiation, which can exceed $15,000 per month.

Unfortunately, while living donation has been proven to be safe, living donation rates have stagnated, if not declined, over the past 20 years. Data from the Organ Procurement Transplant Network (OPTN), created by Congress to facilitate more transplants, document that over the past twenty years deceased donation has increased approximately 250%, while living donation has stagnated.



[9] The Moran Company, The Living Organ Volunteer Engagement (LOVE) Act: Fiscal Implications (March 15, 2024), available from author.

[10] Matas AJ, Montgomery RA, Schold JD. The Organ Shortage Continues to Be a Crisis for Patients With End-stage Kidney Disease. JAMA Surg. 2023 Aug 1;158(8):787-788. doi: 10.1001/jamasurg.2023.0526. PMID: 37223921 ("Given that only about 1% of deaths occur in a manner suitable for organ donation, there appears to be no possibility that any further increase in deceased donation will be sufficient to eliminate the shortage. Similarly, there is currently a considerable emphasis on minimizing the number of deceased donor kidneys recovered but not transplanted; however, at best, that alone might result in approximately 2000 more transplants per year, a mere dent in the problem.").

[11] National Kidney Foundation, Becoming a https://www.kidney.org/kidney-topics/becoming-livingdonor#:~:text=Lasts%20longer%20%2D%20On%20average%2C%20a,away%20than%20deceased%20donor%20kidneys.

Source: https://optn.transplant.hrsa.gov/data/

One reason for this stagnation is that Medicare regulations work against advancing living donation, rather than aiding those with ESKD and advanced CKD in identifying living donors and assisting those potential living donors in pursuing the complex and costly process of donating. As a result, for every 100 potential living donors who volunteer and complete the initial screening questionnaire, only seven may make it to donation.[12]

The Solution

Numerous clinical studies have demonstrated that transplant facilitator interventions could materially increase living donor transplantation. Providing a transplant facilitator to the potential recipient to help the individual's friends and family in identifying a living donor and providing a similar transplant facilitator to the potential donor to help them complete the complex pre-donation and donation process would materially increase the number of living donations from today's stagnant rates.[13]

In addition to improving donor identification rates, facilitation programs enable hospitals to schedule surgeries in advance, improving operating room efficiency and optimizing clinical resources. Planned living donor transplants allow both recipients and donors to undergo surgery under ideal conditions, reducing cancellations and improving outcomes.

Assisting Potential Recipients in Identifying Donors: Expecting ESKD patients to find living donors on their own is often unrealistic. Studies, however, have shown that when dialysis patients (or their friends and family) work with a transplant facilitator who helps them develop the language to ask someone to be their living donor, identify potential donors, and even in some cases initiate the outreach for the potential recipient, the likelihood that a living donor can be found significantly increases.[14] By providing this support for those needing a transplant at an early stage, these challenges to completing a living kidney donor transplant can be overcome inexpensively and efficiently.[15] The Johns Hopkins

---

[12] D. Cholin LK, Schold JD, Arrigain S, Poggio ED, Sedor JR, O'Toole JF, Augustine JJ, Wee AC, Huml AM. Characteristics of Potential and Actual Living Kidney Donors: A Single-center Experience. Transplantation. 2023 Apr 1;107(4):941-951. doi: 10.1097/TP.0000000000004357. Epub 2022 Nov 21. PMID: 36476994.

[13] Federal law and regulation requires transplant programs to have adequate support for living donors, 42 C.F.R. § 482.94, including having on staff an "independent living donor advocate team." 42 C.F.R. § 482.98(d). While transplant hospitals do an excellent job at assisting the living donor through the surgical process, there is no federal program or Medicare regulation addressing living donation *before* a living donor arrives at a transplant hospital.

[14] Garonzik-Wang JM, Berger JC, Ros RL, Kucirka LM, Deshpande NA, Boyarsky BJ, Montgomery RA, Hall EC, James NT, Segev DL. Live donor champion: finding live kidney donors by separating the advocate from the patient. Transplantation. 2012 Jun 15;93(11):1147-50. doi: 10.1097/TP.0b013e31824e75a5. PMID: 22461037; PMCID: PMC3374007.

[15] *See also* Killian AC, Carter AJ, Reed RD, Shelton BA, Qu H, McLeod MC, Orandi BJ, Cannon RM, Anderson D, MacLennan PA, Kumar V, Hanaway M, Locke JE. Greater community vulnerability is associated with poor living donor navigator program fidelity. Surgery. 2022 Sep;172(3):997-1004. doi: 10.1016/j.surg.2022.04.033. Epub 2022 Jul 10. PMID: 35831221; PMCID: PMC9633042 ("The Living Donor Navigator (LDN) Program helps patients with end stage kidney disease identify living kidney donors and helps living donors navigate the complex evaluation process. LDN participants have demonstrated a 9-fold increased likelihood of donor screening and 7-fold increased likelihood of donor approval compared to nonparticipants").

"Champions" program reported a massive increase in recipients identifying living donors following the assistance of a facilitator:

> Current educational modalities or interventions do not adequately meet the needs of patients who would like to pursue and identify live donors. Education alone is not sufficient to decrease the anxiety and fear associated with approaching potential donors. **In this trial, LDCs successfully helped increase comfort and decrease concerns associated with approaching a live donor. A dramatic proportion of participants (almost 50%) identified live donors, compared with matched controls for whom no live donors were identified**.[16]

Providing those eligible for transplant with a facilitator using the Hopkins protocols to assist in identifying living donors would add a massive number of new transplants to the system, driving huge savings at a trivial cost.

Assisting Potential Donors: Similarly, giving individuals who volunteer to be considered for living donation a facilitator to help them through the extensive medical testing and eventual surgery has also been shown to multiply the prospects of living donation. In one study at the University of Alabama Birmingham (UAB):

> [i]implementation of a [Living Donor Facilitator] Program was associated with a 9-fold increased likelihood of living donor **screenings and a 7-fold increased likelihood of having an approved living kidney donor among program participants compared to standard of care**."[17]

Again, providing a potential donor with a facilitator would cost a trivial amount, for massive returns. As noted above, today 93 of every 100 potential living donors willing to be screened never make it to donation. Adding facilitators could radically change that figure, and increase living donation an estimated 7 times, so that 49 of the 100 candidates complete the donation process.

Including Facilitator Costs on the Cost Report Should be Non-Controversial: The concept of including transplant facilitators within the transplant center cost report is not novel and fits comfortably within the mainstream of costs that are currently being reimbursed by Medicare through the cost reports. Under applicable regulation[18] and CMS guidance,[19] organ acquisition cost reimbursement today pays tissue typing, donor and beneficiary evaluation, organ preservation and perfusion costs, OPTN fees, surgery costs to recover deceased donor organs, procurement costs charged by other organizations in the system, and deceased donor organ transportation costs. Not inappropriately, the transportation

[16] *Id.*

[17] Locke, J., et al. Enhanced Advocacy and Health Systems Training through Patient Navigation Increases Access to Living Donor Kidney Transplantation, Transplantation. 2020 Jan; 104(1): 122–129. doi: 10.1097/TP.0000000000002732.

[18] 42 C.F.R. § 413.402.

[19] CMS Pub. 15-1, Ch 31 §3101.

costs include private jet transport of deceased donor organs, which can cost tens of thousands of dollars per donation. Yet, when it comes to living donors, there is no regulation or guidance that would allow a transplant hospital to put the costs of a facilitator on the cost report, even though it may be a material to the transplant happening.

The reimbursement of acquisition costs on the cost report began in 1974, and has been expanded over the years. Since 1978, all organ preservation and perfusion costs have been designated as "Pass Through Costs" and are payable through the cost report, as are other direct and indirect costs associated with operating a transplant program. In contrast, CMS regulations prohibit payment for travel, room and board expenses incurred by the living donor or recipient. Ironically, Medicare is already indirectly paying for hidden facilitation costs, along with numerous other costs that transplant hospitals may not directly bill for, if those services are provided by a third party. There are several organizations in the U.S. that match living donors or create donor chains that charge transplant programs an acquisition fee for procuring the donation, which in turn the transplant center includes on the cost report. Embedded in the acquisition fee can be facilitator costs, travel costs, and even legal support costs. Thus, given that Medicare may, in some cases, already be paying for these costs indirectly, it makes sense for Medicare to pay for them directly as well.

In comparison to paying thousands of dollars for private jet transportation, paying for the few hundred dollars it might cost for a facilitator to assist in arranging a living kidney donor transplant is more than reasonable. Finally, there is a significant need for further steps to increase living donation as a result of an alarming trend overtaking the transplant community. More specifically, in response to media reports of irregularities in deceased donation organ recovery, tens of thousands of Americans have recently (in 2025) withdrawn their consent to be a deceased donor.[20] Thus, as the availability of deceased donor organs declines due to external events, it is even more imperative to ensuring living donors can fill in the gaps.

Implementing these modest changes would likely double the number of living donors within a few years, improving outcomes, reducing the waitlist, and saving Medicare an estimated $6.6 billion over ten years. These reforms could result in more than 40,000 kidney transplants annually—12,000 to 13,000 from living donors alone—representing one of the few policy changes in healthcare that simultaneously improves survival, enhances quality of life, and reduces long-term federal spending. The LOVE Act would ensure that every American in need of a kidney has a timely path to transplant.

[20] https://www.newsweek.com/thousands-remove-organ-donor-registries-nyt-coverage-2109940