

Living Donor Kidney Transplantation **A Failed American Enterprise**



US Kidney Transplant Facts and Insights

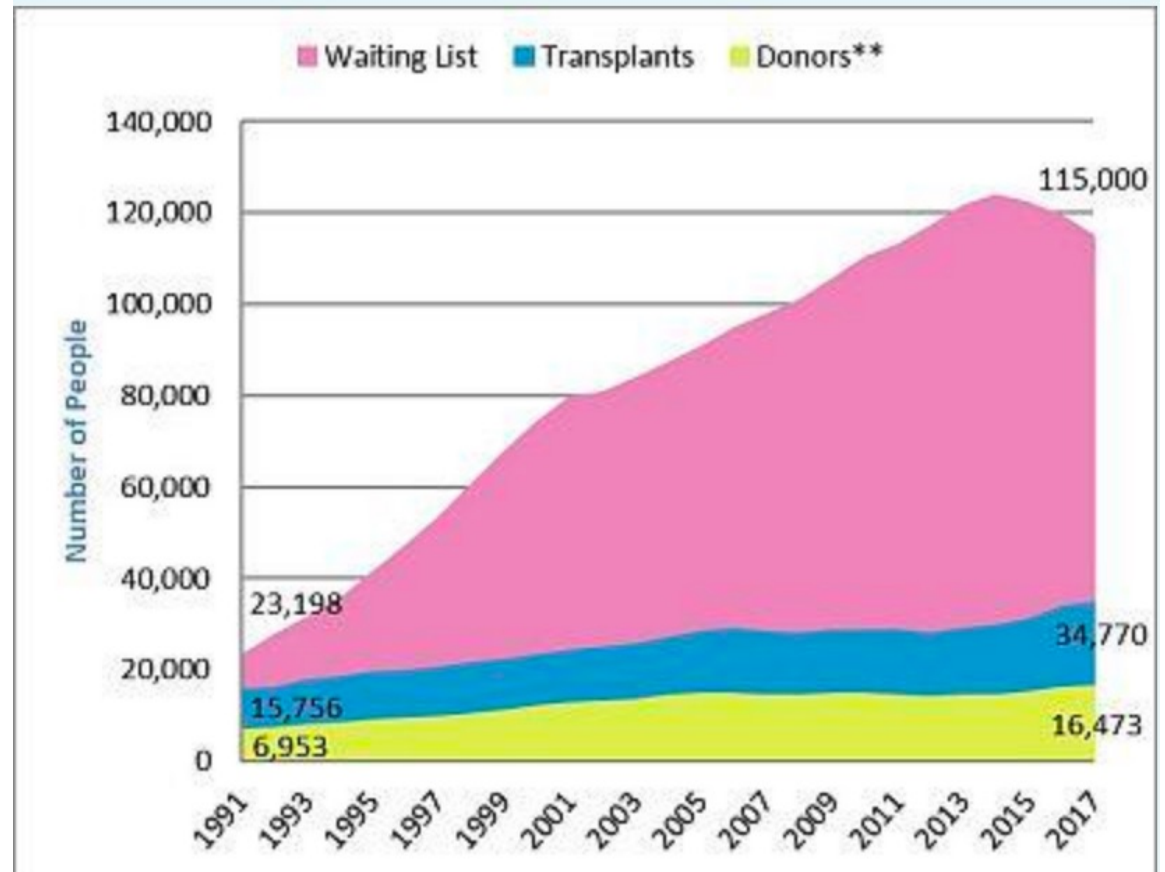
Facts	Insights
93,000 Americans are on the wait list for a kidney transplant.	<ul style="list-style-type: none"> The wait list is growing faster than transplants are available.
The average wait for a kidney transplant is 3-5 years .	<ul style="list-style-type: none"> 12-17 persons die every day waiting for a donor kidney.
Donor kidneys can come from deceased or living donors but living donor organs are far better for a recipient.	<ul style="list-style-type: none"> Living kidney donation is safe. A living donor kidney lasts twice as long as a kidney from a deceased donor. A Living donor kidney is not at risk of discard compared to a deceased donor kidney.
A kidney transplant saves at least \$136,000* per transplant over 10 years with transplant being the best treatment for end stage renal failure,	<ul style="list-style-type: none"> Doubling the living donor rate saves at least \$816 million.

Unfortunately, living donation today is a **flawed US cottage industry**.

Twenty years of education and local programs **have not increased** the living donor transplant rate.

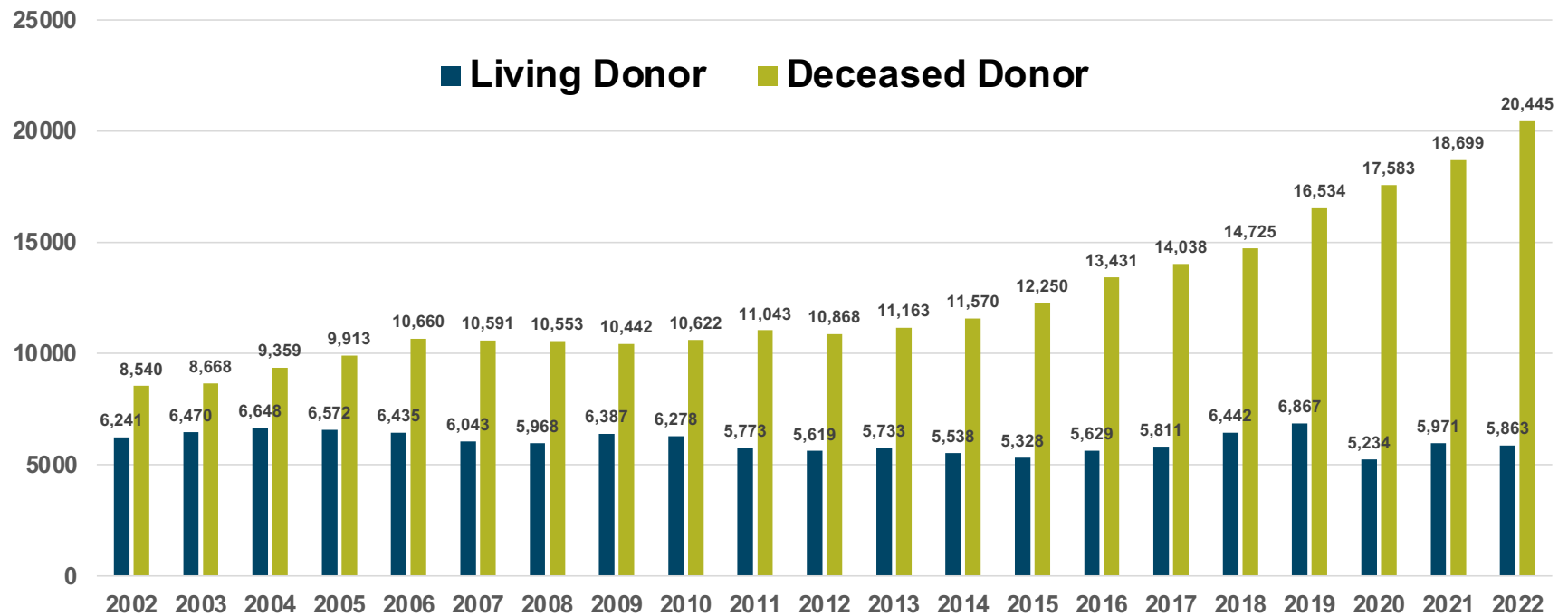
A Broken Living Kidney Donor System

**The number #1
unmet need in kidney
transplantation today
is the lack of
available kidneys to
be transplanted.**



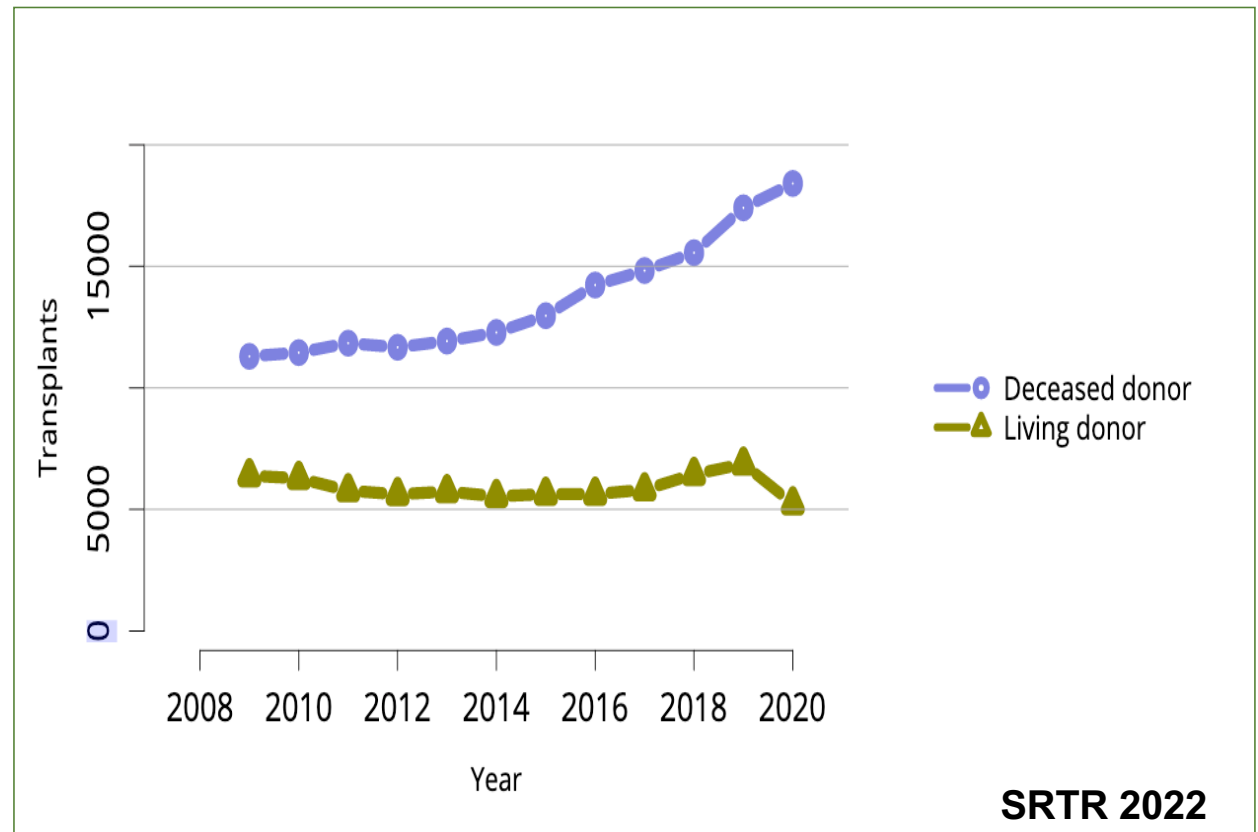
US Living & Deceased Kidney Transplant Comparison (2002-2022)

Why is Living Kidney Donation so Low?



Deceased & Living Donor Kidney Transplants in the US: 2009 – 2020

Another Example of the Failure of Living Kidney Donation in the US



US Kidney Transplants in 2022 Compared with Ten Prior Calendar Years

Year	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022
All	16,487	16,896	17,108	17,878	19,060	19,849	21,167	23,401	22,817	24,670	26,308
Deceased Donor	10,868	11,163	11,570	12,250	13,431	14,038	14,725	16,534	17,483	18,699	20,445
Living Donor	5,619	5,733	5,538	5,628	5,629	5,811	6,443	6,867	5,234	5,971	5,863

All transplants: +9,821 (+59.6%)

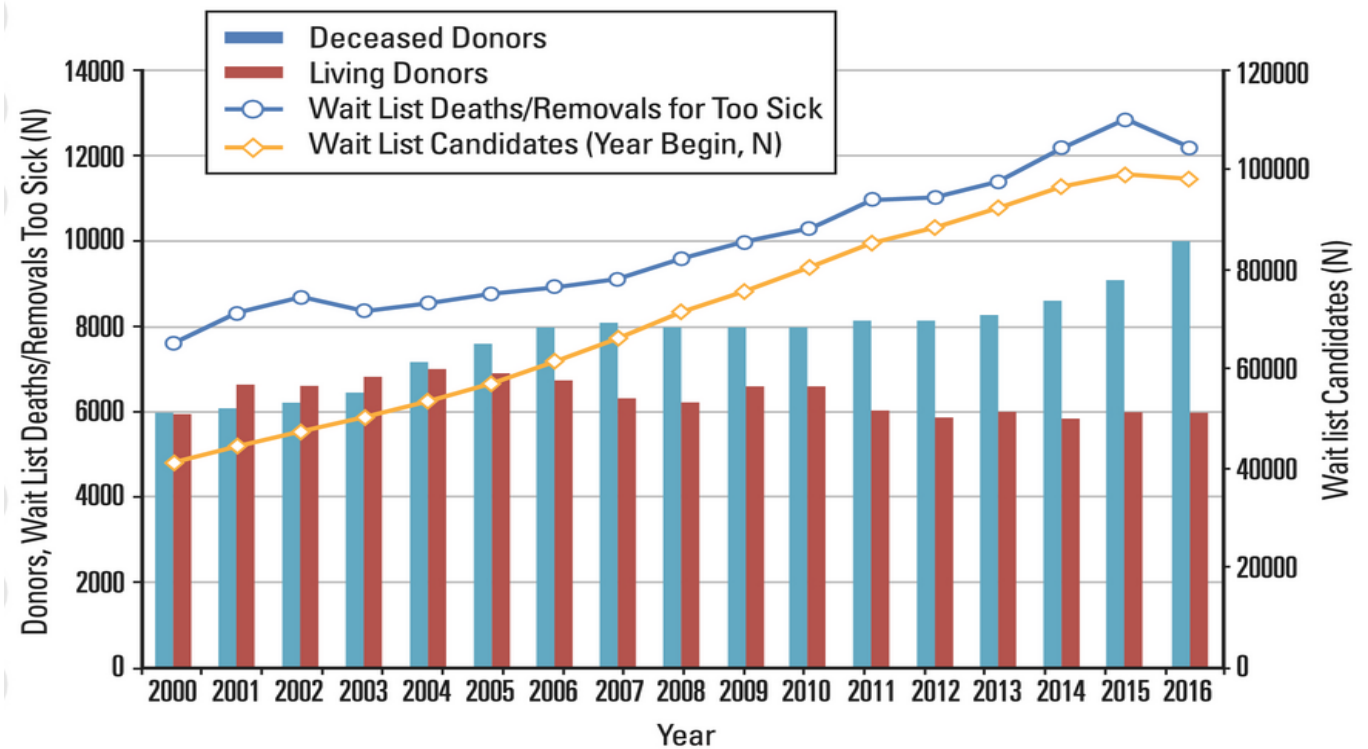
Over the Past Decade: Deceased donor transplants: +9,587 (+88.2%)

Living donor transplants: +244 (+4.3%)

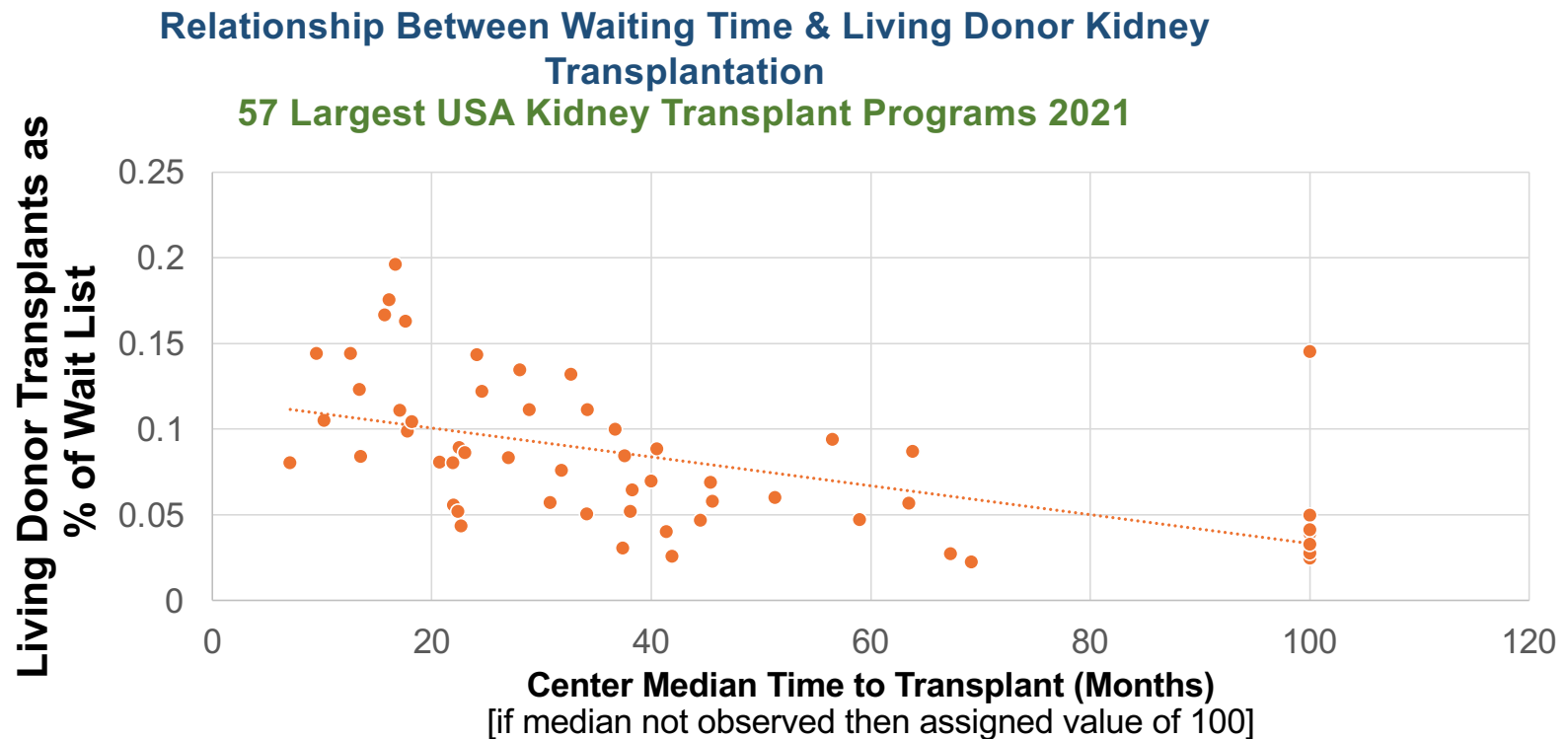
The twenty-year trend is not any better for living donations

While the Kidney Transplant Waitlist and Deaths Grow

The Number
of Living
Donors
Decrease



The Fewer Living Donation Transplants, the Longer the Wait Time



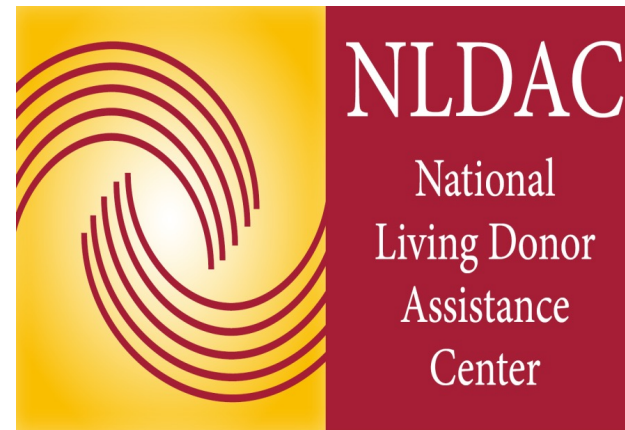
National Living Donor Assistance Program



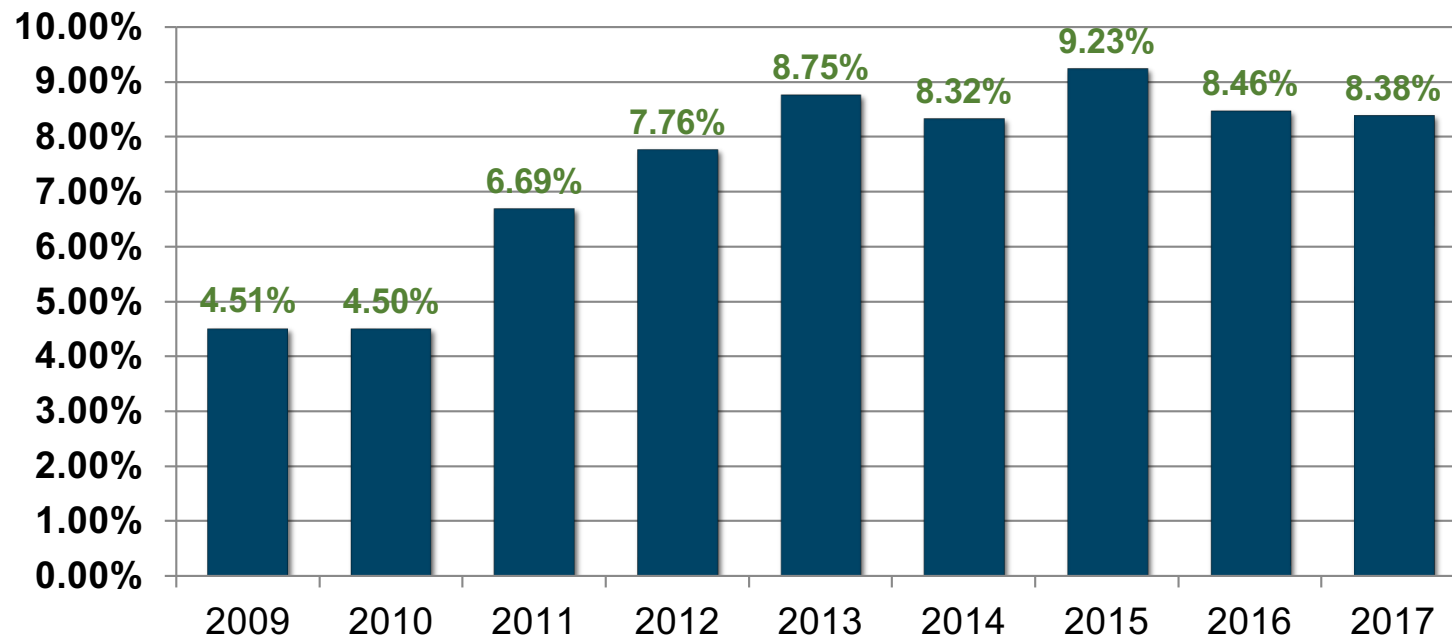
National Living Donor Assistance Center



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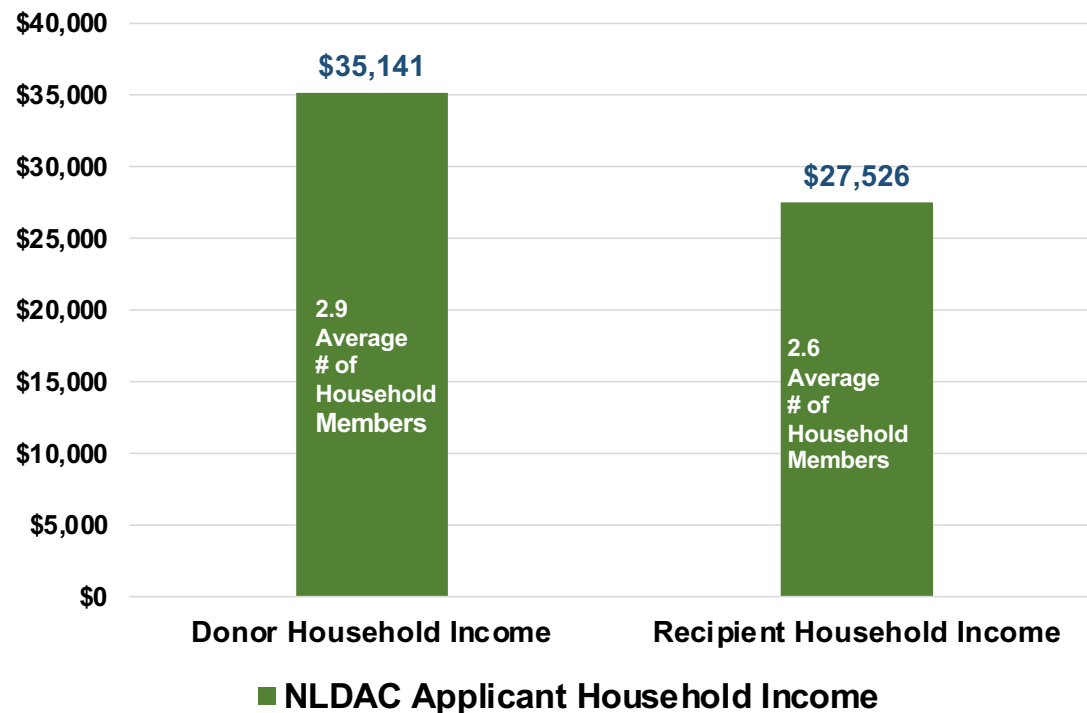


Percentage of US Living Donors with NLDAC Support



2013 – 2017: NLDAC supports approximately 500 Living Donors per year.

NLDAC Living Donor and Recipient Average Income



“Paying donation-related travel costs through NLDAC increased the number of living donor kidney transplants by approximately 14 percent over baseline in participating transplant centers, with a separate survey of NLDAC donors revealing that 75 percent of donors would not have donated without reimbursement. In addition, tax incentive legislation in New York increased living kidney donations to non-family members by 52 percent.”
HRSA Final Rule, Removing Financial Disincentives to Living Organ Donation, 85 Fed. Reg. 59438 (Sep. 22, 2020)

A Solution

Increase Living Kidney Donation by...

- Promoting a national public education effort.
- Establishing a dedicated national program to collaborate and provide better coordination and support for donors.
- Empowering donors with donor navigators to assist with process and logistical issues.
- Removing burdensome donor roadblocks.
- Making donation cost neutral and provide reimbursement for donors (NLDAC)
- Funding a national program to increase living kidney donation to save Americans living with ESRD.
- Will save significant costs and improve health outcomes.



Recent Publications Highlight the Issues

Commentary

Many a Slip Twixt the Intake Form and the Living Donation

Christina D. Majka, MD,¹ and Daniel C. Brennan, MD²

Living donor kidney transplant (LDKT) results in superior allograft and patient survival to deceased donor transplant.¹ Despite this, only 30% of kidney transplants in the United States are from living donors, and the rate of LDKT has remained stagnant for a long time.^{2,3} From 2017 to 2019, the United States observed the first significant growth in the number of LDKTs performed.⁴ This momentum was abruptly lost when the COVID-19 pandemic hit in 2020.⁵ Aside from these events, trends in LDKT in the United States have remained puzzling. Increasing LDKT continues to be a challenge for transplant centers across the country.

The study of Choi et al aimed to describe the characteristics of potential and actual living kidney donors in their transplant center to identify barriers to successful LDKT and potential areas of intervention to increase the number of LDKTs.⁶ They divided their living donor process into 5 phases: intake form, immunologic compatibility testing, clinic evaluation, selection committee review, and donation. They found that two-thirds of potential donors dropped out after completion of the intake form. Of these, the main reason was that almost a quarter did not respond to a follow-up phone call. Around 20% were excluded for medical reasons and another 20% for having a body mass index $>35 \text{ kg/m}^2$. Among the few who progressed to the next phase, close to 40% were deemed incompatible on immunologic testing. Of their 2100 potential donors, only 7% proceeded to donation. High dropout rates during the donor process have been demonstrated in other countries.^{6,7} In a single-center study in Korea, a country where the majority of transplants are from living donors, only 30% of potential donors proceeded to donation.

The barriers to LDKT are multifaceted. Some factors are inherent to the donor and are nonmodifiable. In their logistic regression model, Choi et al⁶ found that White race and first-degree relation to the transplant candidate were associated with an increased odds ratio of donation, as

demonstrated in other studies. Some factors, despite being inherent to the donor, can become modifiable by changing external circumstances (Table 1). For example, certain medical conditions such as hypertension and obesity were previously thought to be contraindications to donation but are now considered relative contraindications and modifiable. This change is a result of improvements in knowledge on the long-term outcomes after kidney donation. Trans and blood-type incompatibilities are now largely addressed by kidney paired donation (KPD) programs. Simulations have shown that optimizing KPD can significantly increase the number of LDKTs.⁸ Including compatible pairs in the KPD can increase the numbers even more.⁹ Other modifiable barriers to LDKT relate to the transplant candidate. Interventions like identifying a Living Donor Champion, the social media app Donor (https://www.donorsapp.com/en), and the Big Ask Big Give program of the National Kidney Foundation (https://www.kidney.org/transplantation/livingdonors) have been used to help recipients find a donor.^{10,11} One can argue that many of these donor-candidate barriers should be addressed at a national level because these are shared across centers all over the country. Centralized initiatives like the National Living Donor Assistance Center, which provides financial assistance to donors (https://www.livingdonorassistance.org/), and the American Society of Transplantation Living Donor Toolkit, which helps providers and donors navigate the donor evaluation process, can streamline efforts. Public-private partnerships using the expertise of organizations like the National Kidney Registry and the mandate of the United Network for Organ Sharing may allow for an optimized national KPD program.¹² Legislation to ensure donor assistance and safety, especially pseudonymization, will alleviate a lot of fear and hesitations at multiple levels, from the donor, the provider, up to the transplant center.¹³

Given the dismal number of potential donors who proceed with donation, centers trying to expand their LDKT program should evaluate which interventions

Living kidney donors (LKDs) represent a unique opportunity, in this regard, to increase the total number of transplants performed. However, living donors only contribute approximately 28% of all transplanted kidneys in the United States currently. In the absence of a nationwide database that captures the predonation process and phases, little is known about LKDs and the barriers associated with initiating and completing the donation process. Lack of education of the recipient and donor candidate, the reluctance of recipients to ask family and friends to donate, and logistical issues (ie, transportation, finding childcare, getting time off of work to go to the appointments) may impact the decision to become a donor. Furthermore, for those interested in becoming a living donor, the evaluation process is extensive. Donor applicants must have optimal overall health, consistent health maintenance follow-up after donation, and adequate social and financial support to be able to afford the costs associated with donation.

Living donor kidney transplant (LDKT) results in superior allograft and patient survival to deceased donor transplant. Despite this, only 30% of kidney transplants in the United States are from living donors, and the rate of LDKT has remained stagnant for a long time..... many of these donor-candidate barriers should be addressed at a national level because these are shared across centers all over the country.

Original Clinical Science—General



Characteristics of Potential and Actual Living Kidney Donors: A Single-center Experience

Liza K. Cholin, MD,¹ Jesse D. Schold, PhD, MStat, Med,² Susana Arriaga, MA,² Emilio D. Foggia, MD,^{1,3} John R. Sedor, MD,¹ John F. O'Toole, MD,¹ Joshua J. Augustine, MD,^{1,3} Alvin C. Wee, MD,¹ and Anne M. Huml, MD^{1,3}

Background. There are limited data and no national capture of barriers associated with initiating and completing the donation process for potential living kidney donors (LKDs). **Methods.** We performed a retrospective analysis of 3021 intake forms completed for prospective LKDs from 2018 to 2019 at a single transplant center. We analyzed data from all potential donors who completed the intake until they became ineligible or withdrew or donation was complete. We used univariate and multivariate models to evaluate independent factors associated with donation at various stages in the donation process. **Results.** The donation process was deconstructed into 5 steps: intake form, immunologic compatibility testing, clinic evaluation, selection committee review, and donation. The highest percentage of potential donors dropped out after completing the intake form, primarily because of not responding to the follow-up phone call (22.6%). Of 403 potential LKDs that completed immunologic compatibility testing, 30% were ABO or crossmatch incompatible. One-third (33%) of all LKDs completed the donation process. The majority of whom were White (81.2%) and female (80.1%). **Conclusions.** A minority of LKDs applicants make it to donation. Our ability to track all potential LKDs from the initial touch point to the transplant center will help us develop interventions to address barriers to a successful donation. (Transplantation 2022;00: 00–00).

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L.K.C. conceived the research design, data analysis, and writing of the article. J.D.S. participated in research design and data analysis. S.A. participated in data analysis and writing. E.D.F. participated in the performance of the research. J.R.S. participated in the performance of the research. J.F.O. participated in the performance of the research. J.J.A. participated in the performance of the research. A.C.W. participated in the performance of the research. A.M.H. participated in the research design and performance of the research.

Supplemental Visual Abstract: <http://www.kidney.org/TT0273>

Supplemental digital content (SDC) is available for this article. Direct URL citations appear in the printed text, and links to the digital files are provided in the HTML text of this article on the journal Web site (www.transplantation.com).

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Living kidney donor applicant: any person who has started the living kidney donor LKDs evaluation.

INTRODUCTION

There remains a considerable imbalance in the supply and demand of kidney allografts in the United States. In 2019, over 100 000 candidates were listed on the kidney transplant waiting list, with only 23% of those receiving an organ.¹ Given the large discrepancy in available kidneys, various strategies have been implemented to try and bridge this gap. Living kidney donors (LKDs) represent a unique opportunity, in this regard, to increase the total number of transplants performed. However, living donors only contribute approximately 28% of all transplanted kidneys in the United States currently.² In the absence of a nationwide database that captures the predonation process and phases, little is known about LKDs and the barriers associated with initiating and completing the donation process. Lack of education of the recipient and donor candidate, the reluctance of recipients to ask family and friends to donate, and logistical issues (ie, transportation, finding childcare, getting time off of work to go to the appointments) may impact the decision to become a donor.³ Furthermore, for those interested in becoming a living donor, the evaluation process is extensive. Donor applicants must have optimal overall health, consistent health maintenance follow-up after donation, and adequate social and financial support to be able to afford the costs associated with donation.⁴

Don't Let Billboards and Social Media be the National Strategy for Organ Donation

He put up a Times Square billboard in search of a kidney – and saved more lives than his own

Marc Weiner booked one of the world's most visible advertising spots, hoping his life would change. He ended up changing the lives of dozens of others, too



There are more than 253.8 million adults in the nation – most of whom presumably have a kidney to spare. Photograph: Marc Weiner

Marc Weiner has two voices. There is his speaking voice, engaging and booming, sharpened over years in front of the

The people using Instagram to find a life-saving kidney donor

Bo Harris says he was not only looking for an organ donation, he wanted to put a face to his largely invisible kidney disease



When Bo Harris needed a kidney, he reached out via social media. Illustration: Guardian Design

Bo Harris was diagnosed with chronic kidney disease in 2015. In the five years since, he has gone to countless doctor appointments, spent weeks in bed with symptoms of the illness such as severe fatigue and body aches, and even battled and beat lung cancer. But the most difficult part of the journey by far, he says, was pushing the publish button on his first Instagram post searching for a life-saving kidney donation.

"It's very out of my nature to have to ask people for anything, and for this, you have to essentially ask, 'Can you donate an organ so I can continue

Melissa's Story: Finding a Living Kidney Donor Through Social Media

Apr. 14, 2022

"I do not have the words to express how grateful I am for what she has done for me," Melissa Kinnaird said of her live kidney donor. "It has really changed my life, and it has changed my life for the better."



Melissa posted on Facebook in 2021 seeking a perfect match for a live kidney

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How to Use Social Media to Find a Living Donor

How to Use Social Media to Find a Living Donor

February 21, 2020

By Dr. Beje Thomas, Internal Medicine and Nephrology

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A woman used the help of Facebook to find a kidney donor

LIFESTYLE

Social media saving lives

A woman is getting a kidney donation from a stranger

youtube/life

A woman is getting a kidney donation from a stranger after posting about her need on Facebook

Elise Solé



Questions?

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