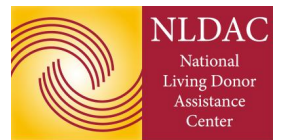
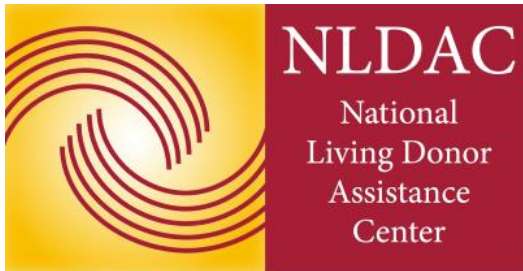


National Living Donor Assistance Center

FEBRUARY 18, 2020





Presenters

Dr. Akinlolu Ojo

- NLDAC Program Director
- Executive Dean, University of Kansas School of Medicine

Ms. Kim Gifford

- NLDAC Program Manager

Ms. Marie-Claire Walters

- NLDAC Sr. Program Assistant



Agenda

- ✓ Program development & outcomes
- ✓ Future growth potential
- ✓ How you can help
- ✓ Q&A

Why Was NLDAC Needed?

Evaluation for living organ donation is costly

Medical costs are generally borne by the intended recipient's insurance

Direct out-of-pocket costs for travel, lodging, food, etc., are usually not covered by the donor or the recipient's insurance

Lost wages are generally not reimbursed

A few programs existed to help, but many potential donors who were otherwise willing were not coming forward because of personal financial disincentives



NLDAC is Regulated by Federal Law

National Organ Transplant Act (NOTA)

- “Valuable consideration” does not include costs associated with travel, housing & lost wages for living donors

Organ Donation Recovery and Improvement Act (ODRIA)

- Authorized grants for living donor travel
- Government is payer of last resort
- Must determine if insurance company or state agency can reimburse donor
- Must determine if recipient can reimburse donor
 - Means test recipient income



National Living Donor Assistance Center

Mission: To reduce the financial disincentives to living organ donation.

Established in 2006 through a collaborative agreement with Health Resources and Services Administration (HRSA), Division of Transplantation (DoT).

There have been 3 additional competitive renewals since inception. Current funding runs through August 2024 with \$3.25M available each year.

Program Goals

Implement NLDAC in collaboration with HRSA/DoT

Provide financial assistance for qualifying expenses to eligible potential live organ donors in the U.S.

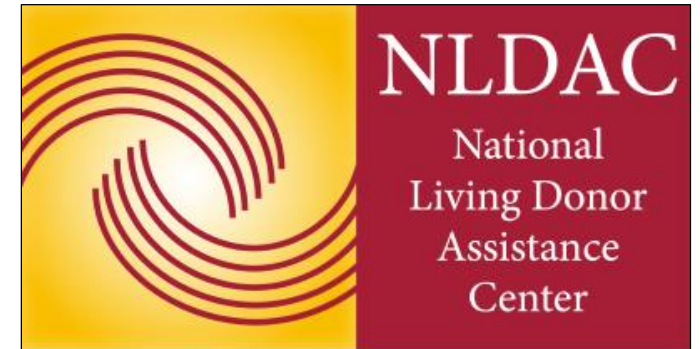
Work with transplant centers, dialysis centers and other stakeholders to reach potential live organ donors

Monitor, evaluate, and disseminate program results

Collaborative Project/Program Team



=



Advisory Group

- Provide input into the development of policies
- Monitor outcomes & performance
- Contribute expertise



Advisory Group Composition



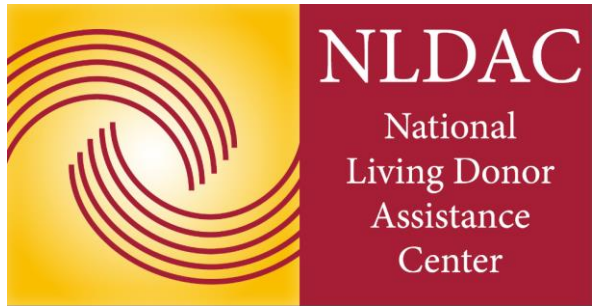
Economist

Donor Representative

Recipient Representative

Transplant Administrator

Program Outcomes



Program Snapshot

96% of eligible transplant centers have filed at least one application

92.7% kidney donors

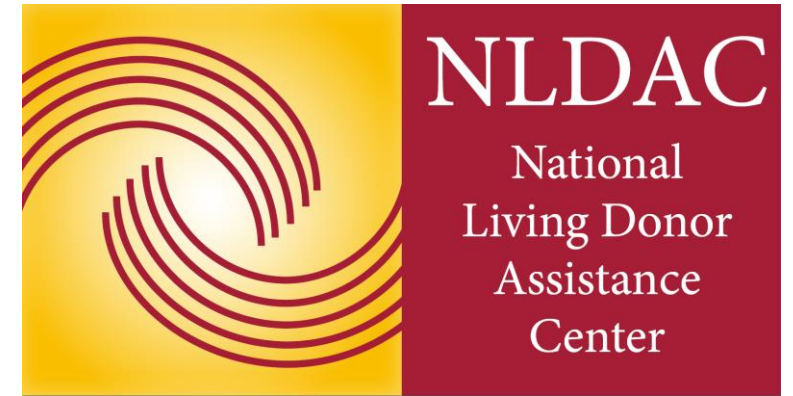
7.3% liver donors

~120 program participants are traveling each week

Overall Program Experience

September 2007 – November 30, 2019

Total applications:	10005
Percent approved:	88.5%
Surgeries complete:	5376
Donor travel paid:	\$18,732,401.21

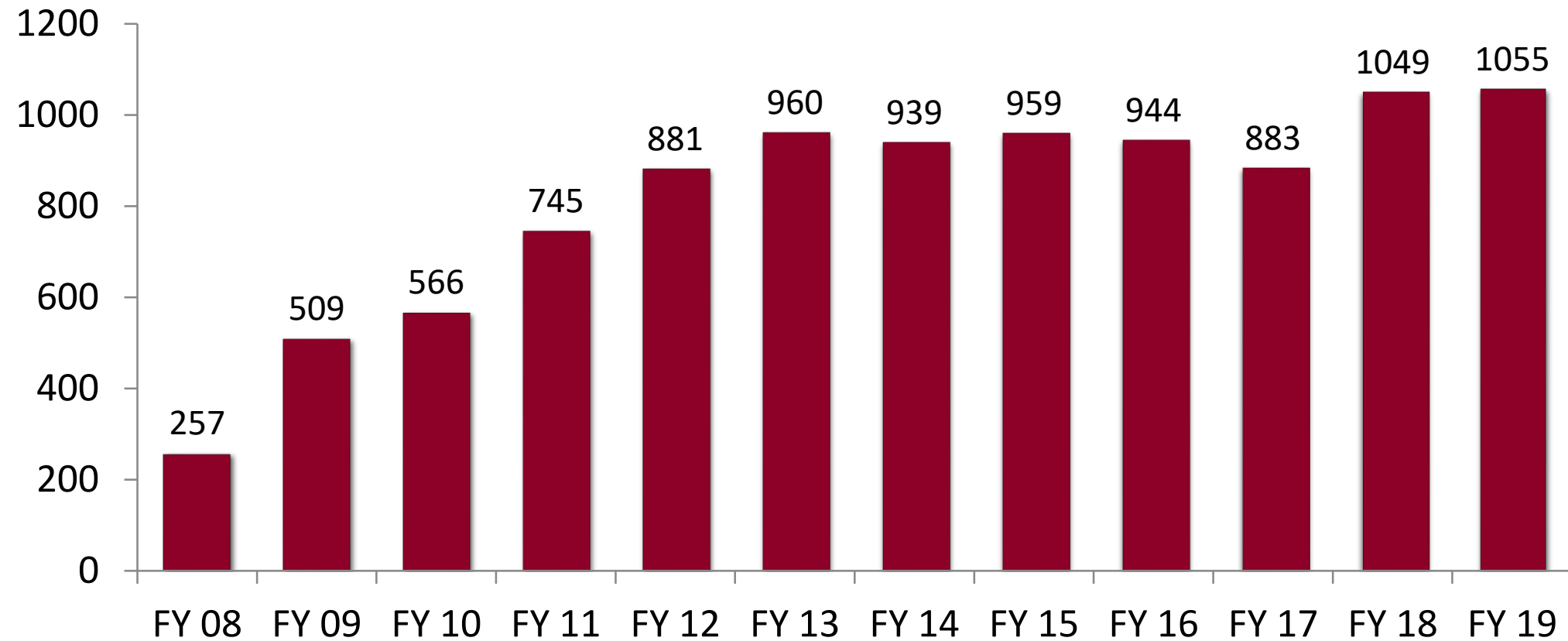


Overall Impact

75% of NLDAC donors report that the program made it possible for them to donate.

Given the 5376 surgeries reported to date, NLDAC has helped over **4,000** people donate that could not have done so otherwise.

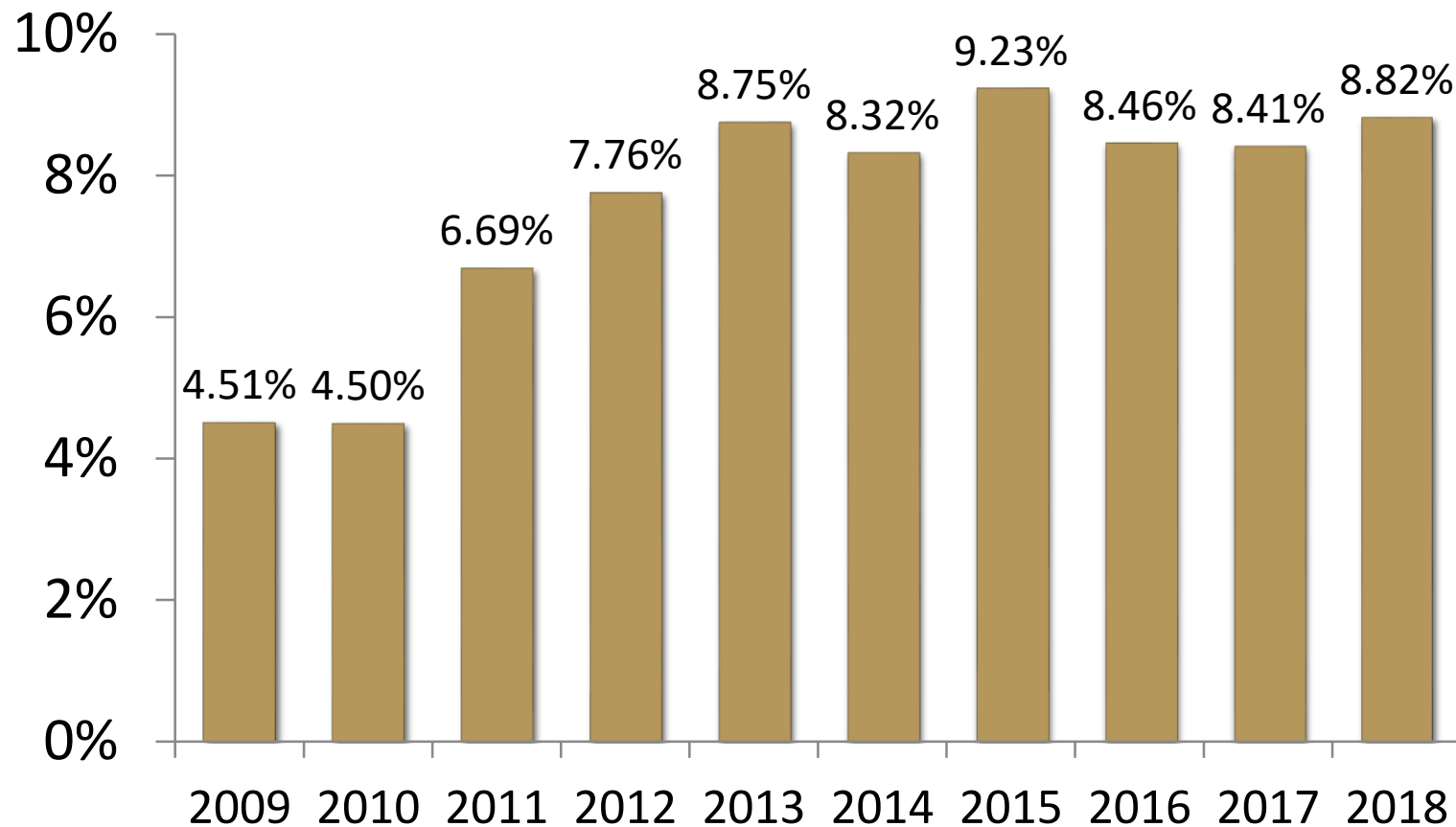
Applications Received



NLDAC Database September 5, 2019

FY September 1 – August 31

% U.S. Living Donors with NLDAC Support



Donor and Recipient Eligibility: 300% FPG

Household Number	48 Contiguous States and DC
1	\$37,470
2	\$50,730
3	\$63,990
4	\$77,250
5	\$90,510
6	\$103,770
7	\$117,030
8	\$130,290

Recipient HH #: 2.5

Donor HH #: 2.9

FY19 Median Income:

Recipient: \$31,722

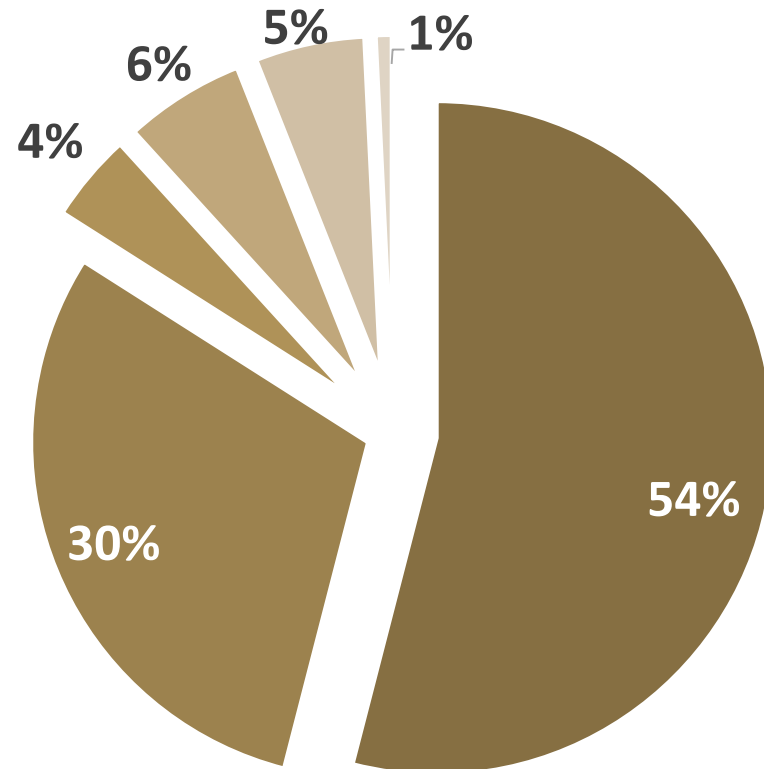
Donor: \$45,731

	NLDAC Recipient Demographics	NLDAC Donor Demographics
Average age	45	41
Female	42.7%	65.3%
Male	57.3%	34.7%
Black/African-American	16.4%	14.3%
Hispanic	19.6%	18.5%

Demographics

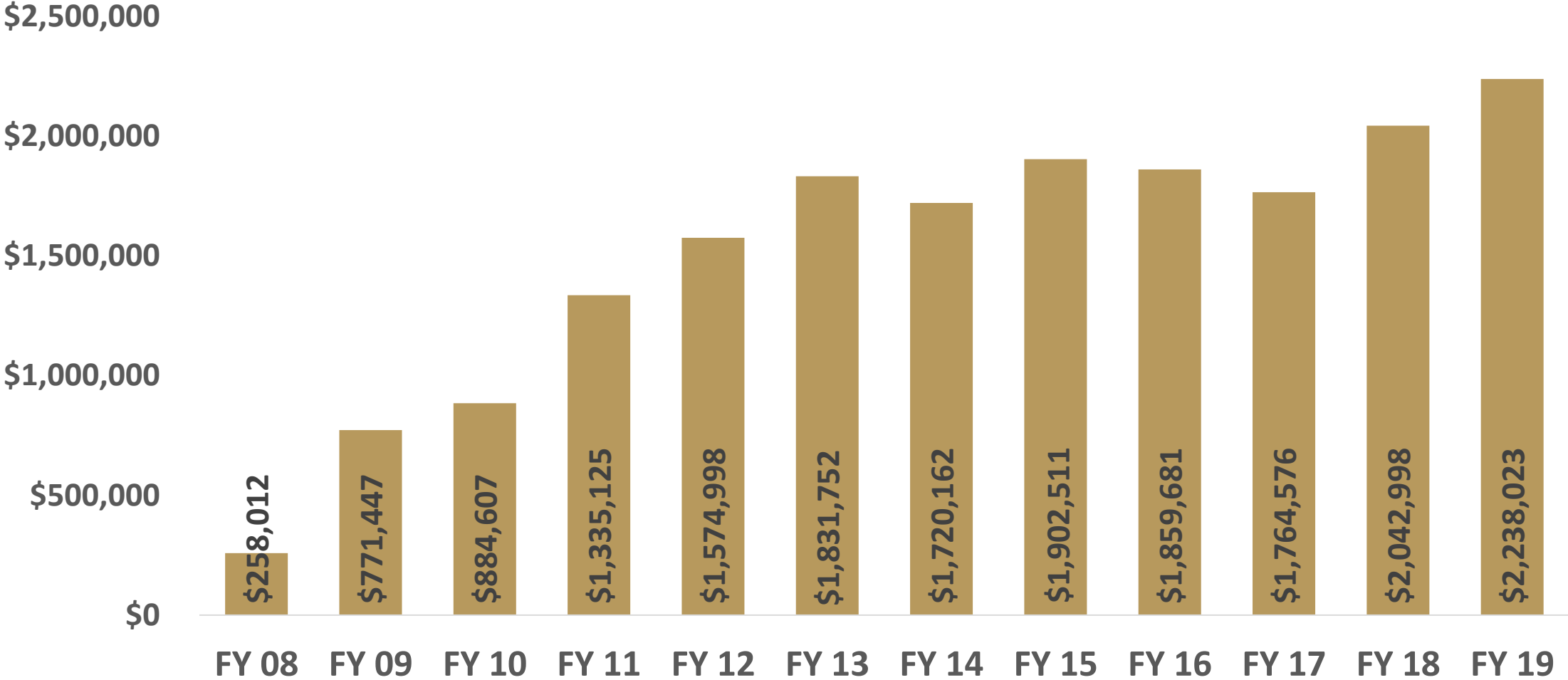
Overall Outcomes

October 2007 – August 31, 2019



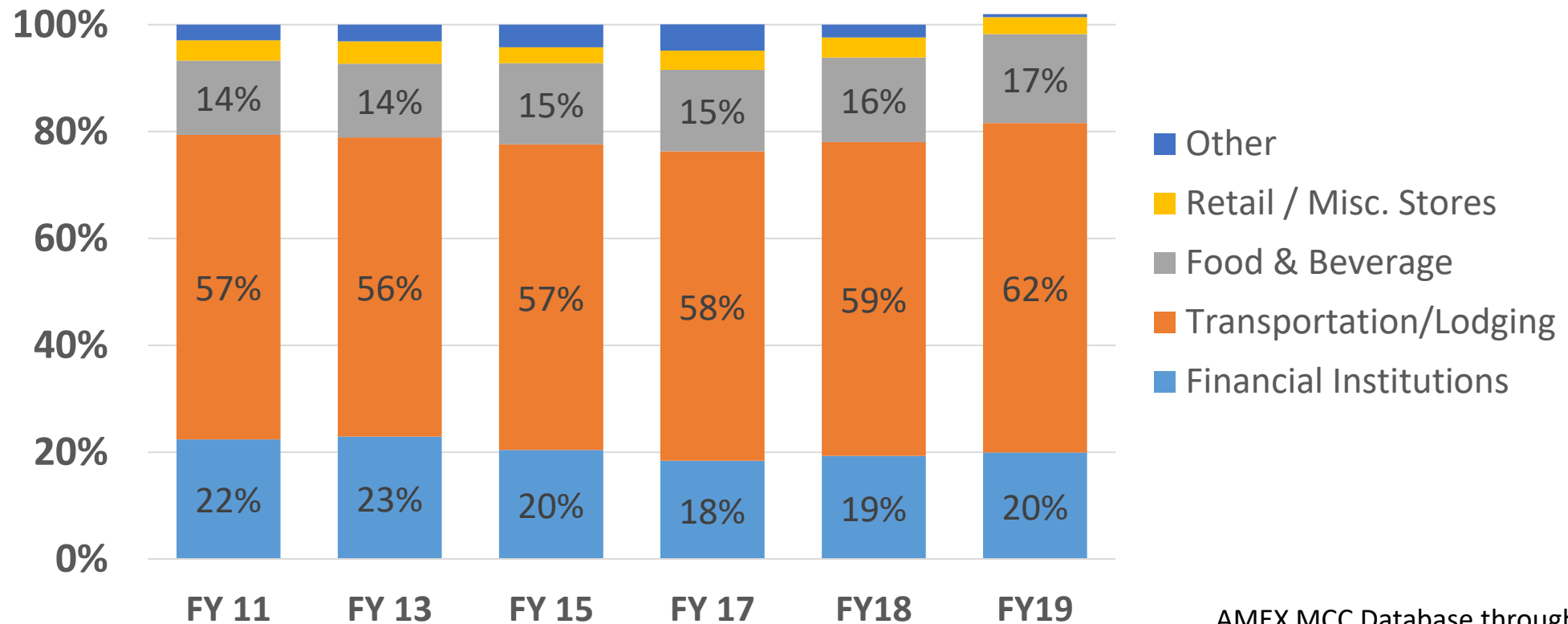
- Surgery Complete (54%)
- Surgery Ruled Out (30%)
- Surgery Pending (4%)
- Application Withdrawn (6%)
- Not Approved (5%)
- Filed Too Late 1%

Donor Travel: Annual Expense



AMEX Report

Donor Spend by Merchant Category by FY



AMEX MCC Database through 8/31/19

Looking Ahead

Lost Wages: Overview

Pilot project to test the impact of lost wage reimbursement on the decision to donate

Funded through: HRSA

Allowable amount: Up to \$5K in lost wage reimbursement (\$8K combined maximum if also using the travel program). No means testing.

Program Team Institutions:



Program Aims

Assess the effect of reimbursement of lost wages on the decision of individuals to initiate evaluation for living organ donation

Inform the US Health Resources and Services Administration (HRSA) on the most effective and efficient mechanism to provide this support to living donors

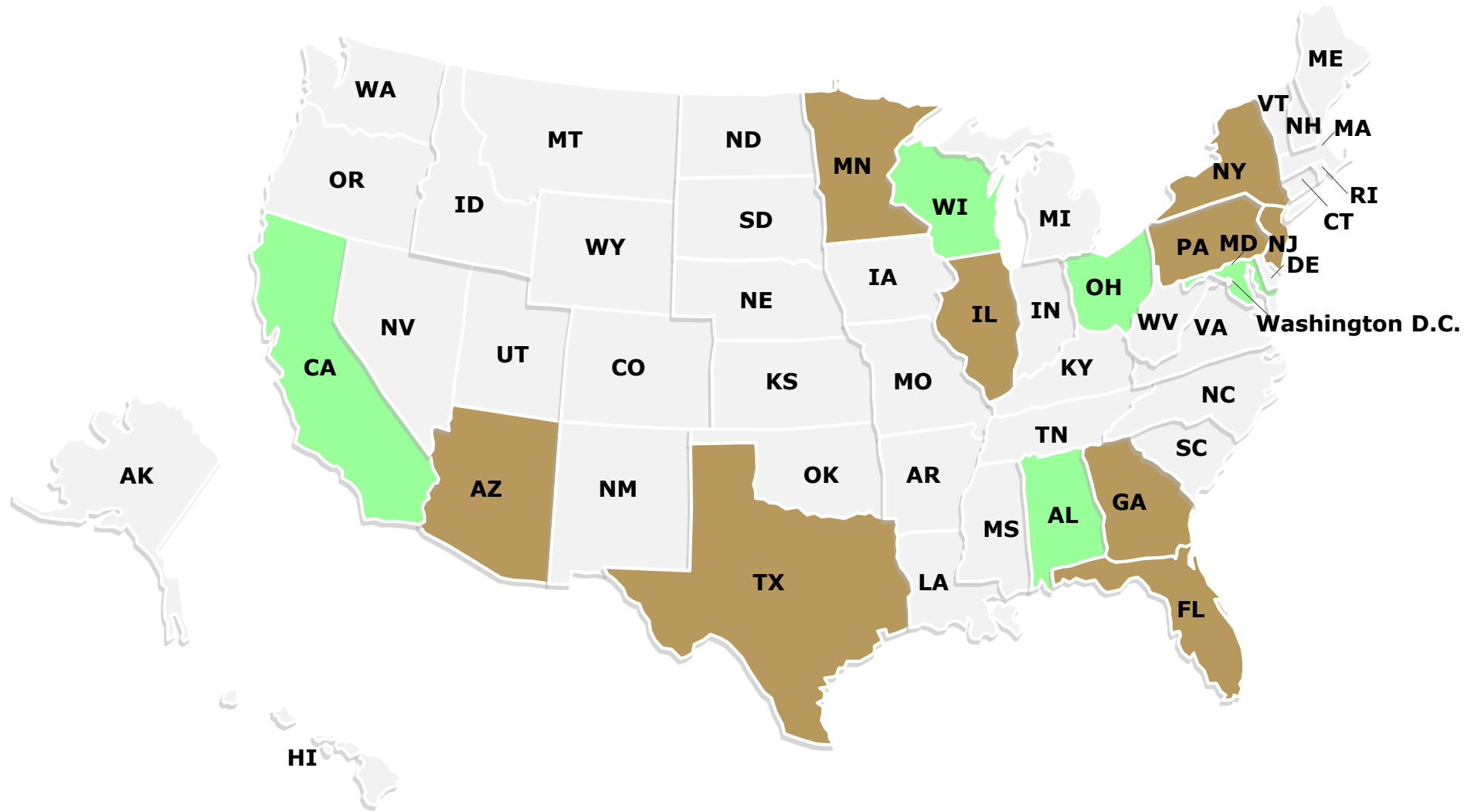
Potential Impact

“Invisible donors”

- How many people are refraining from coming forward as potential donors in part or entirely because of the lost wages issue?
- What are the characteristics of “invisible donors” who are elicited as a result of the demonstration project?

Proposed demonstration project participation guidelines will be indifferent to the phase of evaluation at the time of application

- Maximize catchment of donors who actually incur lost wages
- Provide information about client satisfaction, logistics, and organizational efficiency



Geographic Diversity

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FOR IMMEDIATE RELEASE
December 17, 2019**Contact: HHS Press Office**
202-690-6343
media@hhs.gov

Trump Administration Proposes New Rules to Increase Accountability and Availability of the Organ Supply

The U.S. Department of Health and Human Services (HHS) today took major steps to increase the availability of organs for the 113,000 Americans on waitlists for lifesaving organ transplants – 20 of whom die each day. As directed by President Trump in his July 10 [Executive Order on Advancing American Kidney Health](#), the Centers for Medicare & Medicaid Services (CMS) is issuing a proposed rule to change the way organ procurement organizations (OPOs) are held accountable for their performance, and the Health Resources and Services Administration (HRSA) is issuing a proposed rule to remove financial barriers to living organ donation.

“Our broken system of procuring organs and supporting kidney donors’ costs thousands of American lives each year,” said HHS Secretary Alex Azar. “President Trump sees kidney disease as a health challenge where we can make a major impact, and his Advancing American Kidney Health initiative, including today’s announcements, will transform the lives of American kidney patients, who have been neglected for too long. Many organ procurement organizations do wonderful work, but some aren’t performing nearly as well as they could. We’re going to stop looking the other way while lives are lost and hold OPOs accountable. On living donations, we’re going to dramatically expand support for living kidney donors, so that Americans who wish to be generous living donors don’t face unnecessary financial barriers to doing so.”

Proposed Rule

RELEASED:

DECEMBER 17, 2019

Key Components

- ❑ Proposes to expand the scope of reimbursable expenses to include lost wages, child-care, and elder-care expenses.
- ❑ Proposes to determine that certain categories of “incidental non-medical expenses” are appropriate for reimbursement.
- ❑ Notes that HRSA is preparing a separate notice that would increase the income threshold for eligibility.

Resources

Fact sheet:

Federal Register posting:

Comments due: **February 18, 2020** at .

How you can help

Patient Concerns

“I don’t want to ask my friends and family to donate, because I know it would be too expensive for them to travel to appointments.”

“A friend told me they are willing to donate, but they can’t afford the travel costs.”



Requirements

Donor and recipient must be US citizens or lawfully admitted residents

Donor and recipient must have their primary residence in the US or its territories (Puerto Rico, Guam, etc.)

Recipient's income should be within NLDAC's income guidelines (after financial hardship is considered)

Income Guidelines

- Income guidelines are 300% of Federal Poverty Guidelines
- If the recipient's household income exceeds our income guidelines, we have to assume they could help their donor with travel expenses, unless they request a waiver for financial hardship.
- No income limits for donors

300% 2020 Federal Poverty Guidelines			
# of people in household	48 contiguous states & DC	Alaska	Hawaii
1	\$38,280	\$47,850	\$44,040
2	\$51,720	\$64,650	\$59,490
3	\$65,160	\$81,450	\$74,940
4	\$78,600	\$98,250	\$90,390
5	\$92,040	\$115,050	\$105,840
6	\$105,480	\$131,850	\$121,290
7	\$118,920	\$148,650	\$136,740
8	\$132,360	\$165,450	\$152,190

What does NLDAC provide?

Transportation – plane tickets, gas, rental car, taxis, parking, tolls, etc.

Hotel – at the federal lodging rate

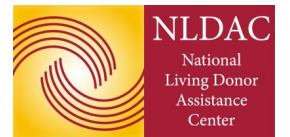
Meals – at the federal per diem rate

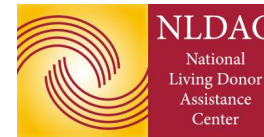
Limits

- Expenses can be covered on evaluation, surgery and follow-up trips for the donor
- 2 trips for a support person
- Maximum \$6,000

Who submits the application and when?

- Transplant center staff (donor social workers, nurse coordinators) file applications
- Application can be submitted as soon as the transplant center decides to evaluate a potential donor
- NLDAC only covers expenses that donors incur after their application has been approved, so the application must be submitted and reviewed before the appointment the donor needs help with
- Application must be approved and funded before surgery





What do my patients need to know?

NLDAC is a travel program for living organ donors (we cannot pay for recipient travel)

We pay for living donors' transportation, hotel, and meals in advance

The donor's eligibility depends on the recipient's household income

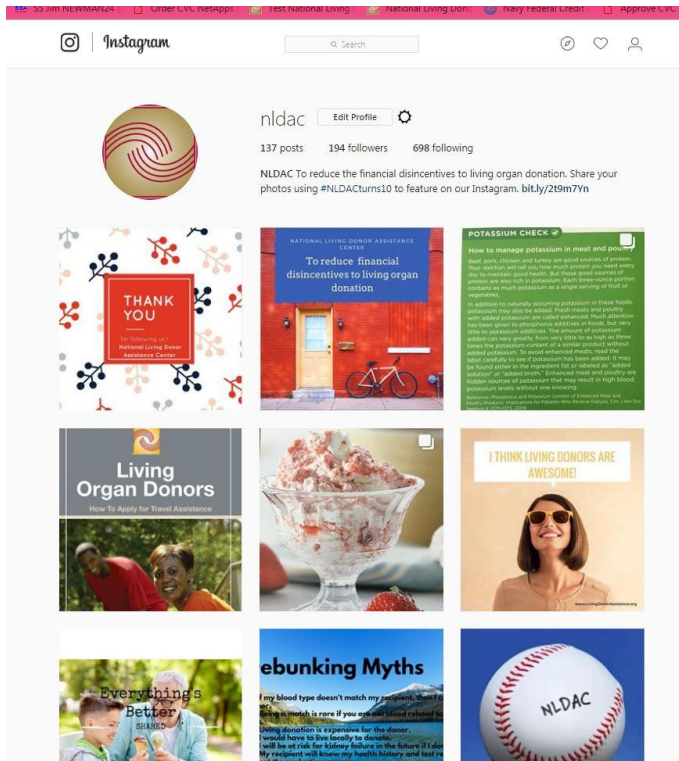
Donors and recipients can call us at **888-870-5002** or visit **LivingDonorAssistance.org** to learn how to apply

What should my patients do?

- Call our office or check our website to find out if their income is within our guidelines.
 - Phone: (888) 870-5002
 - Website: LivingDonorAssistance.org
- If their income is within our guidelines, when they talk to people about their search for a living donor, mention there is a program that can pay for the donor's travel expenses.

What should my patients do?

- Encourage their potential donors to call our office or talk to their social worker at the transplant center to learn about the program and how to apply before their first evaluation.
- Complete the application worksheet so it is ready when the transplant center asks for it.



NLDAC on Facebook, Instagram and Twitter

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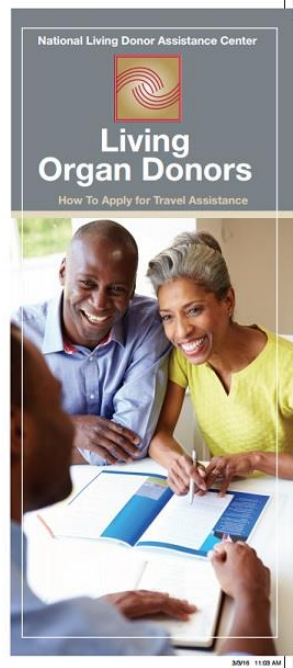
Help for Living Kidney Donors



The National Living Donor Assistance Center provides financial support for travel to the Transplant Center for eligible living donors. Approved donors receive a credit card to pay for expenses up to \$6,000, including:

- Transportation
- Lodging
- Food
- Travel for the donor's support person

For more information call the National Living Donor Assistance Center (NLDAC) at 888-870-5002 or visit our website: LivingDonorAssistance.org

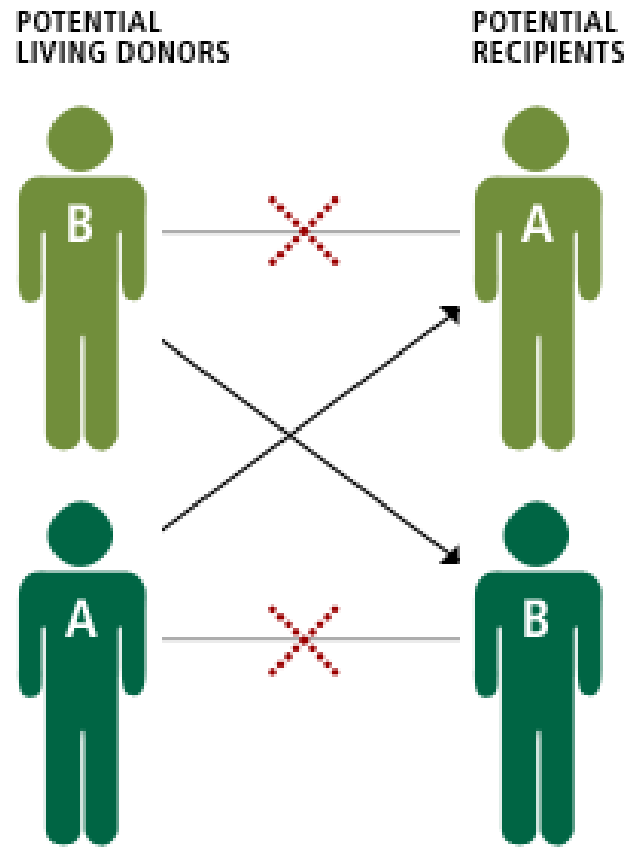


Downloadable Resources

www.LivingDonorAssistance.org

Ask your questions!

Kidney Paired Donation



Financial status of the originally intended recipient shall be considered on the application