National Living Donor Assistance Center

ROBERT MERION, MD
NLDAC PROGRAM DEPUTY DIRECTOR
NOVEMBER 1, 2017
Objectives

Describe the purpose of the NLDAC
Describe the risks and benefits of living organ donation
Describe the history and funding of the NLDAC
Describe program eligibility
Review program outcomes
Describe NLDAC support provided to living kidney donors
Program Goals

01 Implement NLDAC in collaboration with HRSA/DoT (collaborative effort – not contractor)

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

03 Work with all transplant centers in the U.S. to reach potential live organ donors

04 Monitor, evaluate, and disseminate program results
The Challenge

Source: www.unos.org, accessed 8/9/17
Benefits of Living Donation

No medical benefits for a living organ donor

Many living donors derive psychological benefit and emotional satisfaction by helping a loved one

Society benefits from living donation

- Reduced pressure on the deceased donor system
- More people transition from dialysis to transplant, which saves lives and saves money
- Living donor transplants function longer than deceased donor transplants, reducing the need for repeat transplant procedures
Risks of Living Donation

- Minor and major complications related to surgery
- Altered body image/scarring
- Death is rare, but can occur (~3 in 10,000 risk)
- Very small excess risk of kidney failure in the long term, but not zero
- Time off work; lost wages
- Insurance/insurability issues
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 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
Funding: Health Resources and Services Administration (HRSA), Division of Transplantation (DoT)

Competitive grant awarded in 2006, 2010, and 2014 to the University of Michigan in partnership with the American Society of Transplant Surgeons, Arbor Research Collaborative for Health, Washington University, and Mayo Clinic, Arizona

In 2016, the grant was transferred to the University of Arizona
Advisory Group 2017

➢ Provide program guidance to the National Living Donor Assistance Center
➢ Meet annually to review outcomes and offer recommendations for improvement
➢ Represent key stakeholders in the dialysis and transplant community
➢ Brenda Dyson represents the ESRD community
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
Eligibility Criteria

Donor and recipient U.S. citizens or lawfully admitted residents

Travel U.S. or it’s territories

Donor and recipient have primary residence in U.S. or territories

Donor & recipient attest that they are not exchanging money for organs
Kidney Paired Donation

Financial status of the originally intended recipient shall be considered on the application.
Federal law states funds from NLDAC may not be used if payment for donor expenses have been made, or can reasonably be expected to be made:

- under any state compensation program, under an insurance policy, or under any federal or state health benefits program
- by an entity that provides health services on a prepaid basis
- by the recipient of the organ
  - (Recipient household income determines eligibility for NLDAC)
All applications are means tested and assigned a preference category.

<table>
<thead>
<tr>
<th>Category 1</th>
<th>Income is below 300% Federal Poverty Guidelines (FPG)</th>
<th>Income is below 300% Federal Poverty Guidelines (FPG)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category 2</td>
<td>Income is below 300% FPG</td>
<td>Income is above 300% of FPG, must demonstrate financial hardship</td>
</tr>
<tr>
<td>Category 3</td>
<td>Income is below 300% FPG</td>
<td>Does not need to demonstrate financial hardship</td>
</tr>
<tr>
<td>Category 4</td>
<td>Income is above 300% FPG, must demonstrate financial hardship</td>
<td>Income may be above or below 300% FPG</td>
</tr>
</tbody>
</table>
Qualifying Expenses

Travel, lodging, meals & incidental expenses

- Up to $6,000
- 3 Trips for the donor
- 2 Trips for the support person
- Up to 2 years after surgery
- Transportation, lodging, & subsistence expenses
- Federal per diem rate for meals
  - Paid at the rate for transplant center city
- Hotel up to 150% federal per diem rate
Controlled Value Cards (CVC)

Electronic Donor Accounts

- Excludes merchant codes not related to travel
- Funds can be added or removed in seconds
AMEX Report
Donor Spend by Merchant Category by FY

<table>
<thead>
<tr>
<th>Merchant Category</th>
<th>FY 09</th>
<th>FY 11</th>
<th>FY 13</th>
<th>FY 15</th>
<th>FY 17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food &amp; Beverage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Institutions</td>
<td>15.6%</td>
<td>13.9%</td>
<td>13.8%</td>
<td>15.2%</td>
<td>15.2%</td>
</tr>
<tr>
<td>Other</td>
<td>20.8%</td>
<td>22.4%</td>
<td>22.9%</td>
<td>20.4%</td>
<td>18.4%</td>
</tr>
<tr>
<td>Retail / Misc. Stores</td>
<td>55.2%</td>
<td>57.0%</td>
<td>56.0%</td>
<td>57.2%</td>
<td>57.9%</td>
</tr>
<tr>
<td>Transportation/Lodging</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

AMEX MCC Database through 8/31/17
Program Snapshot

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

93.4% kidney donors

6.5% liver donors

~100 program participants are traveling each week
Applications Received

<table>
<thead>
<tr>
<th>Year</th>
<th>FY 08</th>
<th>FY 09</th>
<th>FY 10</th>
<th>FY 11</th>
<th>FY 12</th>
<th>FY 13</th>
<th>FY 14</th>
<th>FY 15</th>
<th>FY 16</th>
<th>FY 17</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>257</td>
<td>509</td>
<td>566</td>
<td>745</td>
<td>881</td>
<td>960</td>
<td>939</td>
<td>959</td>
<td>944</td>
<td>883</td>
</tr>
</tbody>
</table>

NLDAC Database September 8, 2017
FY September 1 – August 31
Overall Program Experience

SEP 2007 – AUG 2017

Total applications: 7638
Percent approved: 88.8%
Surgeries complete: 4028
Donor travel paid: $13,901,460.61
Donor Travel: Annual Expense

FY 08: $258,012
FY 09: $771,447
FY 10: $884,607
FY 11: $1,335,125
FY 12: $1,574,998
FY 13: $1,831,752
FY 14: $1,757,522
FY 15: $1,902,511
FY 16: $1,859,681
FY 17: $1,764,576

NLDAC Database August 31, 2017
FY September 1 – August 31
Overall Impact

4028 Donor surgeries completed;

75% of actual donors report they could not have donated without NLDAC support;

Without the program, 3021 fewer transplants would have occurred since 2007.
% U.S. Living Donors With NLDAC Support

Calendar Year - OPTN Data 9/08/17 - NLDAC Data 9/08/17
#NLDAC Turns 10
How to Apply to NLDAC

HOLLY WARREN, RN
PROGRAM COORDINATOR
NOVEMBER 1, 2017
Goal:

Ensure all eligible patients know about the NLDAC program and have access to the funding.
Eligibility 300% Poverty Guidelines
Recipient’s income determines eligibility

<table>
<thead>
<tr>
<th># Person Household</th>
<th>48 Contiguous States and DC</th>
<th>Alaska</th>
<th>Hawaii</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>$36,180</td>
<td>$45,180</td>
<td>$41,580</td>
</tr>
<tr>
<td>2</td>
<td>$48,720</td>
<td>$60,870</td>
<td>$56,010</td>
</tr>
<tr>
<td>3</td>
<td>$61,260</td>
<td>$76,560</td>
<td>$70,440</td>
</tr>
<tr>
<td>4</td>
<td>$73,800</td>
<td>$92,250</td>
<td>$84,870</td>
</tr>
<tr>
<td>5</td>
<td>$86,340</td>
<td>$107,940</td>
<td>$99,300</td>
</tr>
<tr>
<td>6</td>
<td>$98,880</td>
<td>$123,630</td>
<td>$113,730</td>
</tr>
<tr>
<td>7</td>
<td>$111,420</td>
<td>$139,320</td>
<td>$128,160</td>
</tr>
<tr>
<td>8</td>
<td>$123,960</td>
<td>$155,010</td>
<td>$142,590</td>
</tr>
</tbody>
</table>

Source: HHS Federal Poverty Guidelines (FPG) 2017
Who has preference?
Applications submitted to NLDAC receive preference based on household incomes of the recipient and the donor. See the NLDAC Preference Category Matrix below. Currently, preference category 2 applications are not being accepted.

**NLDAC Preference Category Matrix**
Applicants will be given preference in the following order of priority:

<table>
<thead>
<tr>
<th>Category</th>
<th>Recipient</th>
<th>Donor</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Category 1</strong></td>
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<td>Income is below 900% FPG</td>
<td>Income is above 300% of FPG, must demonstrate financial hardship</td>
</tr>
<tr>
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<td>Income is below 300% FPG</td>
<td>Does not need to demonstrate financial hardship</td>
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Qualifying Expenses

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- Up to $6,000
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- Up to 2 years after surgery
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- Federal per diem rate for meals
- Hotel up to 150% federal per diem rate
Three Steps to NLDAC Application Process
How to Apply

Complete NLDAC Application Worksheet
❖ Donor Application Worksheet
❖ Recipient Application Worksheet

Worksheets Available
❖ www.LivingDonorAssistance.org
❖ 888-8970-5002
❖ Ask Transplant Professional
www.LivingDonorAssistance.org

Application
Worksheets
& Videos
Pasos para presentar la "Hoja de Trabajo" de NLDAC y el formulario de Declaración.

1. **Consértese y firme la Hoja de Trabajo de NLDAC**
   - **Hoja de Trabajo (Cómodo y Pobre Form: Declaración (Especial)**
   - **Hoja de Trabajo del Paciente y Form: Declaración (Pobre de Bienes)**
   - **Hoja de Trabajo del Paciente y Form: Declaración (Pobre de Ingresos)**

2. **Además de una copia de uno o más de los siguientes documentos para verificar su ingreso familiar**
   - **Declaración de Ingresos**
   - **Certificado de Beneficio del Seguro Social**
   - **Certificado de Ingresos de los Jueces**
   - **Certificado de Ingresos de los Jueces**
   - **Certificado de Ingresos de los Jueces**

3. **Entrega** estos documentos a su Coordinador de Transplante, Trabajador Social u otro profesional de Transplante. Este profesional presentará la solicitud al nombre del donante. No envíe las visas de trabajo a NLDAC. No solicite actividades directamente de los pacientes.

www.LivingDonorAssistance.org
NLDAC Application Worksheets and Attestation Forms

Donor and Recipient must complete:

- **CONTACT INFORMATION**
  - Name, address, email address, ...etc.
- **INCOME INFORMATION**
  - Household income, # members of family
- **ATTESTATION FORM**
  - Form to read and sign

**Donor** must complete additional information:

- **ACCOMPANYING PERSON/CARETAKER**
  - Name, address, trips
- **TRAVEL INFORMATION (ESTIMATED)**
  - Evaluation, Surgery and Follow up
  - Airfare, mileage, public ground transportation
  - Lodging
Gather Income Documents

Income Documents to Verify Household Income

Variety of Documents can be used

- Federal Income Tax Return
- Pay Stubs
- Disability Statements
- Medicaid Eligibility Documents
- Other
Gather Income Information

**Donor and Recipient must provide proof of household of yearly income**

**Tax Return**

**W-2**

*Use Gross Income*

*Use Adjusted Gross Income*
## Requesting a Waiver for Financial Hardship

**Recipient household income above the 300% threshold-need waiver**

Filer send waiver to NLDAC with application

- **Example:** If recipient’s household income is $5,000 above the income threshold, they will need $5,000 in allowable out-of-pocket allowable medical expenses for their donor to qualify.

### 2015 Recipient Financial Hardship Waiver Worksheet

<table>
<thead>
<tr>
<th>Item</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Monthly out-of-pocket insurance premiums</td>
</tr>
<tr>
<td>2.</td>
<td>Monthly out-of-pocket pharmacy expenses before the transplant</td>
</tr>
<tr>
<td>3.</td>
<td>Monthly out-of-pocket pharmacy co-pays after the transplant (prescribed by transplant professional)</td>
</tr>
<tr>
<td>4.</td>
<td>Monthly out-of-pocket physician co-pays</td>
</tr>
<tr>
<td>5.</td>
<td>Total hospital/medical bills owed not covered by insurance (not monthly)</td>
</tr>
<tr>
<td>6.</td>
<td>Loss of income due to surgery (excluding paid time-off/disability pay)</td>
</tr>
<tr>
<td>7.</td>
<td>Monthly round trip mileage for medical appointments (pre-transplant)</td>
</tr>
<tr>
<td>8.</td>
<td>Monthly parking (pre-transplant)</td>
</tr>
<tr>
<td>9.</td>
<td>Will you travel to the transplant center for your surgery? (Air, Car, Bus, Train)</td>
</tr>
<tr>
<td>10.</td>
<td>If driving, how many miles round trip to the transplant center?</td>
</tr>
<tr>
<td>11.</td>
<td>If you will stay in a hotel, how many nights will you stay?</td>
</tr>
<tr>
<td>12.</td>
<td>In the Post 3 months after your transplant, how many trips (sedentary, transportation, medical appointments) will you make to the transplant center?</td>
</tr>
<tr>
<td>13.</td>
<td>Monthly independent care for a family member not living in the household - please describe in Comments</td>
</tr>
<tr>
<td>14.</td>
<td>Other expenses - please describe in Comments</td>
</tr>
</tbody>
</table>

*Comments:

\[\text{NATIONAL LIVING DONOR ASSISTANCE CENTER (NLDAC)}\]

**IMPORTANT:** If your household income is above the 300% of the Federal Poverty Guidelines (FPG) (see chart below), you must complete this worksheet and give to your transplant professional. If your income is below 300% of the FPG, you do not need to complete this form. Please list monthly or one time out-of-pocket allowable expenses for your entire household. Regular living expenses (rent, utilities, etc.) should not be included. If you have questions or need more information, call NLDAC staff toll free at 1-888-670-5602.

Filer send waiver to NLDAC with application.
Give Worksheets and Income Documents to your Transplant Professional

Transplant Professionals
- Living Donor Social Worker
- Recipient Social Worker
- Nurse Coordinator
- Financial Coordinator
- Administrator
Who files NLDAC applications at the transplant center?

- Social Worker: 62.4%
- Nursing: 17.3%
- Financial Coord: 7.4%
- Other: 12.8%

NLDAC Database 2016: Filer position NLDAC Applications
Contact a Transplant Professional-Submit Worksheets, Attestation Forms & Income Document

To send:
1. Completed Donor Application Worksheet and signed Attestation Form
2. Donor Household Income Documents
3. Recipient Application Worksheet and signed Attestation Form
4. Recipient Household Income Documents
5. Recipient Waiver of Financial Hardship (if income is above NLDAC guidelines)

Transplant Professional will submit application to NLDAC on behalf of the donor

NLDAC Does not accept applications from patients. Please send documents to the transplant professional who will file the application on behalf of the living organ donor.
<table>
<thead>
<tr>
<th>Barriers</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree or Disagree</th>
<th>Disagree</th>
<th>Disagree Strongly</th>
<th>N/A</th>
<th>Total</th>
<th>Weighted Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not have enough time to complete the application</td>
<td>3.27%</td>
<td>5.88%</td>
<td>8.50%</td>
<td>37.25%</td>
<td>34.64%</td>
<td>10.4%</td>
<td>153</td>
<td>4.05</td>
</tr>
<tr>
<td>Patients do not supply information required for the application</td>
<td>5.23%</td>
<td><strong>32.68%</strong></td>
<td>13.73%</td>
<td>23.53%</td>
<td>15.69%</td>
<td>9.15%</td>
<td>153</td>
<td>3.13</td>
</tr>
<tr>
<td>Determining eligibility is too complicated</td>
<td>0.65%</td>
<td>7.19%</td>
<td>13.73%</td>
<td>32.68%</td>
<td>37.91%</td>
<td>7.84%</td>
<td>153</td>
<td>4.09</td>
</tr>
<tr>
<td>Our transplant center provides donor living accommodations</td>
<td>3.92%</td>
<td>3.27%</td>
<td>5.88%</td>
<td>22.88%</td>
<td>43.14%</td>
<td>20.92%</td>
<td>153</td>
<td>4.24</td>
</tr>
<tr>
<td>Leadership does not support NLDAC usage</td>
<td>1.31%</td>
<td>0.00%</td>
<td>3.92%</td>
<td>17.65%</td>
<td>63.40%</td>
<td>13.73%</td>
<td>153</td>
<td>4.64</td>
</tr>
</tbody>
</table>
Why Applications Not Approved

Recipient income above the income threshold and financial hardship is not proven

Application is filed too late
- 10 business days Preference 1-3
- 15 business days Preference 4
Application Review Process

1. **Receive Application**
2. **Review Committee**
   - Monday Response
3. **Donor/Transplant Center Notified**
4. **AMEX Card Ordered**
5. **Approve/ Deny**

*Weekly Basis*

- Roxanne Taylor, RN MSN – Maine (NATCO)
- Julie LaMantia, MSW, LCSW – Arizona (STSW)
- Debra Washington, – Virginia (NKF)
After Application Approved

NLDAC staff call all approved donors to verify contact information and give verbal instructions.

Approval letter & budget sent to donor via email and application filer is cc’d on email.

AMEX card ordered & electronic account created.
Controlled Value Cards
Electronic Donor Accounts

- Exclude Merchant Codes Not Related to Travel
- Add funding as needed, generally one week before travel
1. Who is Eligible?

2. How to Apply for Travel Assistance

3. What happens after I am approved?
NLDAC Website Poster and Brochure

www.LivingDonorAssistance.org

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 $5,000, including:

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

For more information call the National Living Donor Assistance Center (NLDAC) at 888-305-8502 or visit our website: www.LivingDonorAssistance.org
NLDAC Donor Survey-Approved Applicants

How did you hear about NLDAC?

- Transplant Center: 79%
- NLDAC Website: 3%
- Recipient: 6%
- Friends/Relatives: 2%
- Living Donor Organizations: 1%
- Other: 2%
- NA: 7%
NLDAC on Facebook, Instagram and Twitter

Follow us!
Contact Us – We are happy to help 😊

Kim Gifford, NLDAC Program Manager
Holly Warren, RN, NLDAC Program Coordinator
Iby Diaz, NLDAC Program Assistant Coordinator
  • (Spanish Speaking)
Marie-Claire Walter, Program Assistant
  • (Spanish Speaking)

888-870-5002
nldac@LivingDonorAssistance.org
www.LivingDonorAssistance.org
Office hours:
M-F 9 A.M. to 5 P.M. Eastern time
2461 South Clark Street
Arlington, VA 22202
Kidney Paired Donation

Financial status of the originally intended recipient shall be considered on the application.
Kidney Paired Donation
Sharing Their Experience

Janis Dougan
Steve Engholm

https://www.youtube.com/watch?v=2i4W4tTCSk0