

Increasing Living Donation Awareness In Texas To Increase The Number of Willing Donors

Tracy Giacomma, RN, MSN, MBA, FACHE

– Vice President

Transplant Services

Objectives

- Describe Types of Living Donation
- Identify Benefits of Living Donation
- Identify disincentives to Living Donation
- Detail initiatives by Federal Government, other states and private organizations for increasing Living Donation Awareness and Willing Donors

Organs For Living Donation

- Kidney (donate 1) Most Common and Most Needed
- Liver (donate lobe or portion or domino)
- Lung (donate lobe)
- Intestine (donate portion)
- Pancreas (donate portion)
- Heart (domino transplant)
- Uterus (whole organ under clinical trials)

Types of Living Donor Transplants

Related

- Blood Relative. They can be:
 - Brothers and sisters
 - Parents
 - Children over 18 years of age
 - Other blood relatives (aunts, uncles, cousins, half brothers and sisters, nieces and nephews)

Non-Related

- Unrelated living donors emotionally close to, but not related by blood
- Spouses
- In-law relatives
- Close friends
- Co-workers, neighbors or other acquaintances

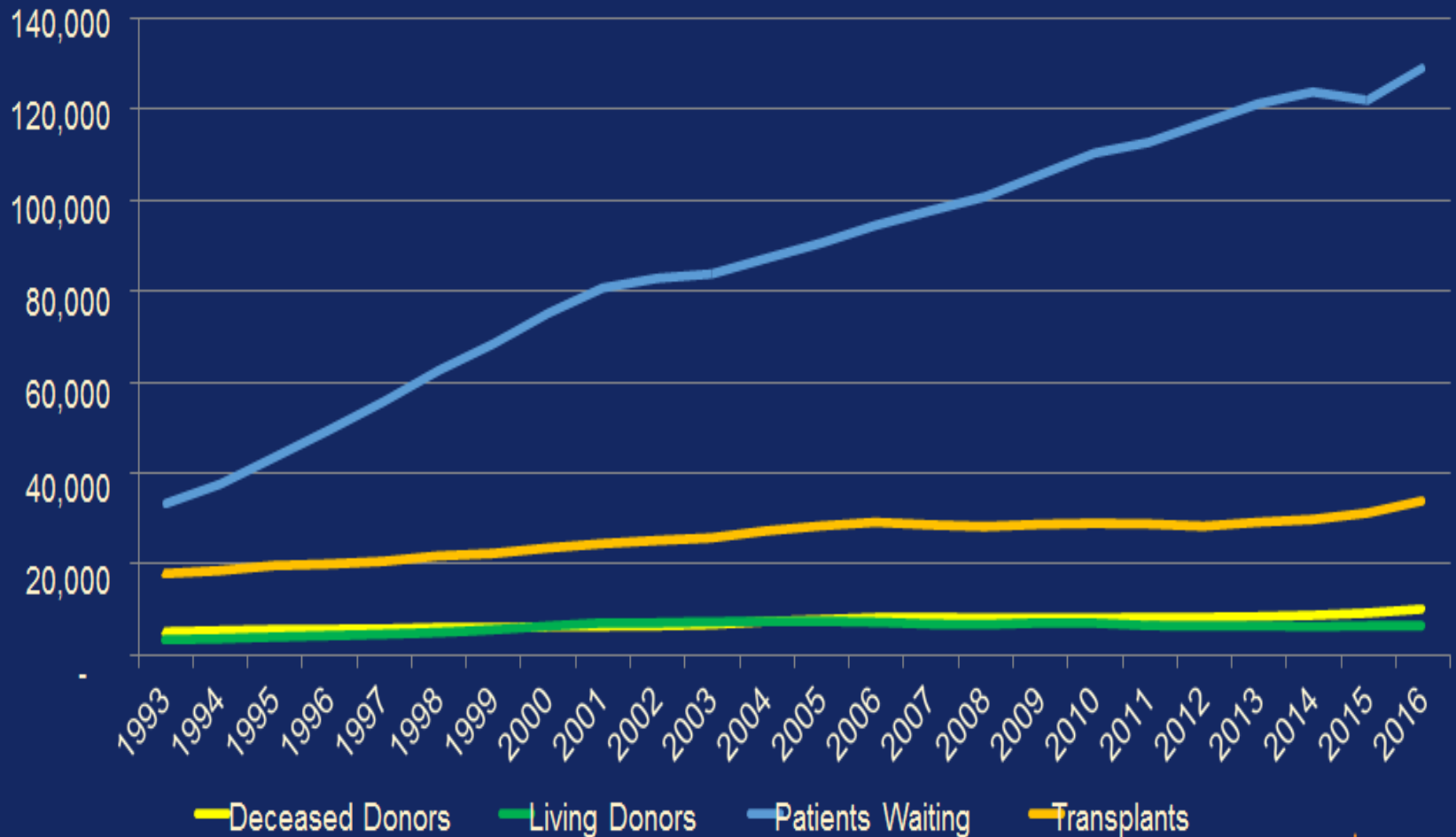
Non-Directed

- Non-directed donors are not related to or known by the recipient, but make their donation purely out of selfless motives
- This type of donation is also referred to as anonymous, altruistic, altruistic stranger, and stranger-to-stranger

Paired donation

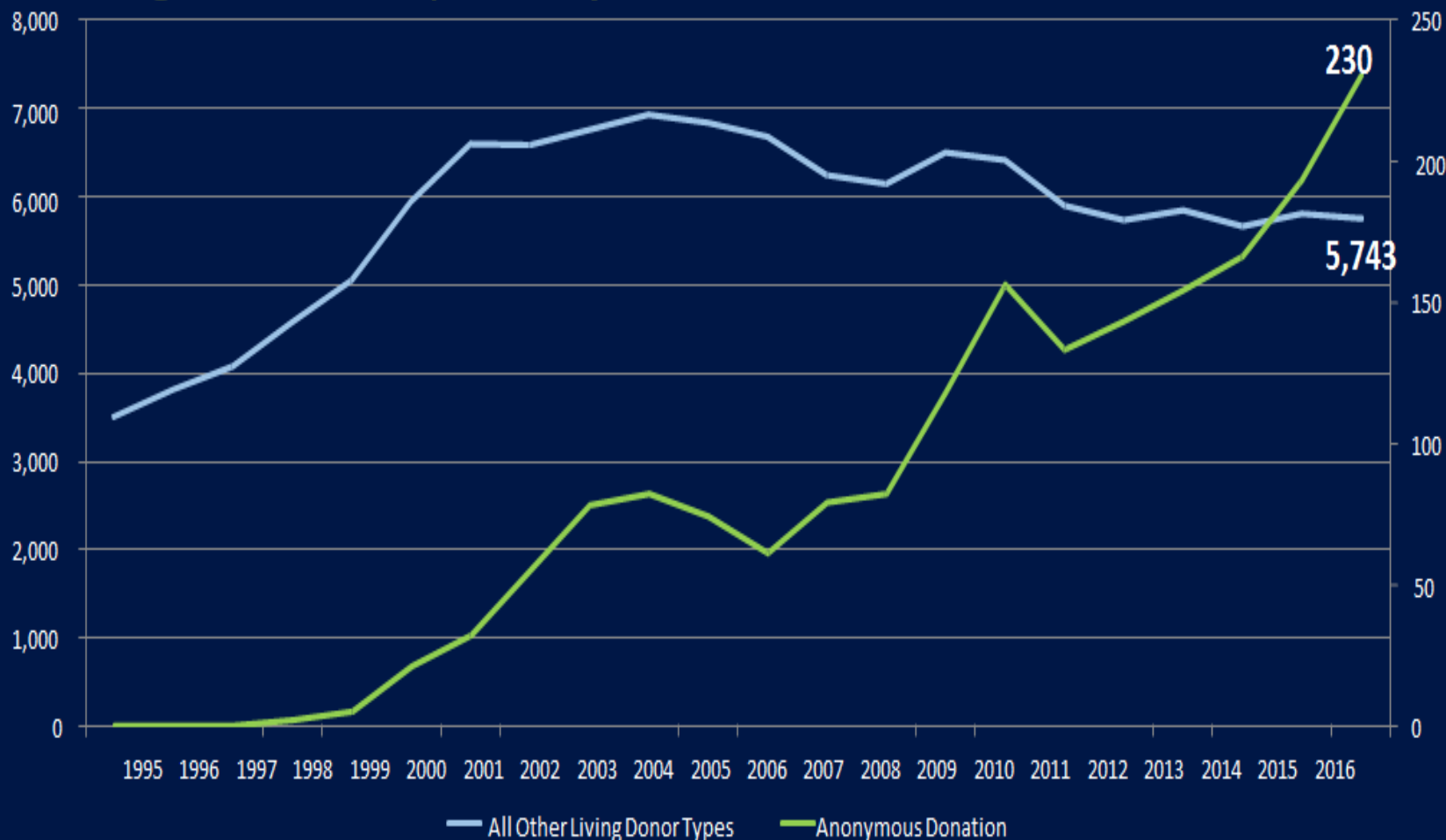
- Living donors who are medically able, but cannot donate a kidney to their intended person because of incompatibility (i.e. poorly matched) can participate in paired donation.
- Paired exchange donation consists of two or more kidney donor/recipient pairs where recipients trade donors so that each recipient can receive a compatible kidney

U.S. Transplant Waiting List, Transplants and Organ Donors



SRTR 2015 Annual Report and OPTN Data from <https://optn.transplant.hrsa.gov/data/view-data-reports/build-advanced/> as of 4/11/2017

Living Donor Transplants by Donor Relation and Calendar Year



OPTN Data from <https://optn.transplant.hrsa.gov/data/view-data-reports/build-advanced/> as of 4/11/2017

Benefits of Living Donation

Better Outcomes

- A living donor kidney functions, on average, 8 to 12 years longer than a deceased donor.
- Patients who get a kidney transplant before dialysis live an average of 10 to 15 years longer than if they stayed on dialysis (this option only exists with living donor transplants)

Lower Cost

- Medicare spends on average \$17,000 a year for the immunosuppressive drugs for a kidney transplant recipient, compared to about \$70,000 for a year of dialysis.¹
- UnitedHealthcare reports that a kidney transplant costs around \$150,000. In contrast, dialysis treatment for person needing a transplant costs about \$260,000, every year. ²
- Living donors decrease or eliminate wait time on dialysis for a transplant.

Rewarding Experience

- Donors feel rewarded as more recipients are transplanted and their families, friends or community are helped by their donation.
- Donors life can be saved if their living donor comprehensive workups uncover unexpected health issues.

The National Kidney Foundation 2016.

UnitedHealthcare 2016

Living Donation Is Embraced by Public

Mayo Clinic Study: 84% would consider donating to friend or family member; 49% would consider donating to stranger¹

NKF survey: 1 in 4 Americans would consider live donation if they knew someone who needed a kidney²

Mayo Clinic. <http://newsnetwork.mayoclinic.org/discussion/mayo-clinic-poll-shows-half-of-americans-would-consider-donating-a-kidney-to-a-stranger>. Accessed July 18, 2016.

National Kidney Foundation. <https://www.kidney.org/news/newsroom/newsreleases/0083>. Accessed July 15, 2016.

Living Donation Is Embraced by Public

200 million Americans ages 18-65 years

If 25% are willing to donate, then 50,000,000 are willing to donate

Need ~25,000 per year and only 1/2000 willing need to be eligible

Where are the donors?

Disincentives to Living Donation

Transplant Coverage and Post Donation Insurability

- Texas Medicaid does not cover Living Donor Transplantation.
- BCBS of Texas sells products not covering Living Donor Transplantation.
- Post donation, the insurance companies are denying or increasing premiums for life, disability and long term care insurance

Costs

- Donors average \$4400 in out of pocket expenses.¹
- Uncovered expenses include ground transportation, healthcare, child care, meals, medications, lodging, air transportation, and lost wages.

Lack of Awareness

- Donors Don't really know they are needed
- Public myths related to living donation include high risk of death, and need for lifelong medications and lifelong dietary restrictions post donation

Initiatives for Finding a Living Donor

Patient Advocate Role:

Not the patients - Most are reluctant to discuss their condition, let alone ask for donors > 60% embarrassed to ask, >80% don't know how to ask

Separating the advocacy role from the patient will help to overcome communication-related barriers associated with identifying a live donor

Live Donor Champion – Friend, family, or community member or stranger trained to advocate on behalf of the transplant candidate and spread awareness

Initiatives for Finding a Living Donor

Social Media or Websites:

Many patients use social media to share their story, which may reach a larger group of people.

Be careful with social media. Some people have tried to take advantage of a patient's vulnerability by offering to donate a kidney for money. This is illegal..

Initiatives for Finding a Living Donor

National Kidney Foundation's"

Program:



**A CONVERSATION
CAN SAVE A LIFE.**

Whether you need a kidney or are considering donation, let us help you start the conversation.



UNOS Patient Resources



Initiatives For Education On Need For Living Donation

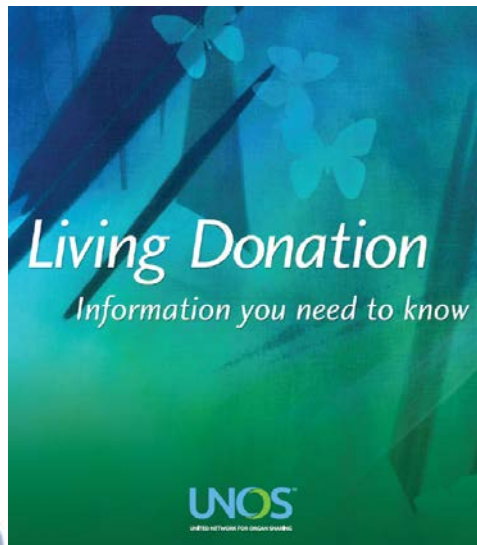
- Living Kidney Donors Network (LKDN) Religious and Fraternal Education Initiative educates members of these groups about the need for living kidney donors.
- It is a national volunteer program made up of kidney donors and transplants recipients facilitated by LKDN.

Initiatives For Education On Becoming a Living Donor

UNOS Transplant Living

Organ facts Before After **Living donation**

Become a living donor



Living Kidney Donation: What You Need to Know

ASTS - American Society of Transplant Surgeons / Resources /




Living Kidney Donation English

ASTS educational videos are not meant to replace the informed consent process that takes place between the transplant candidate and the transplant center. They are designed to inform individuals who wish to learn more about transplantation and are not meant as medical advice.




Methodist
DALLAS

Initiatives For Reducing Financial Disincentives For Living Donation



National Living Donor Assistance Center

10 Years

Our Mission

To reduce the financial disincentives to living organ donation

The U.S. Department of Health and Human Services will provide up to \$3.5 million yearly for donor travel expenses through August 31, 2019.



Patient Assistance Program

Our program is designed to provide lifesaving monetary assistance for the most vulnerable patients with significant financial hardship. Our goal is to provide support so they won't be in a financial trouble after giving the Gift of Life.

Please Note: We are experiencing a drastic increase in requests for lifesaving funds already in 2018 and therefore are only able to consider the **most financially vulnerable** transplant patients at this time. Our program funds continue to be capped at \$700 for living donors.

Initiatives For Reducing Financial Disincentives For Living Donation

[Cigna](#) has provided a travel benefit for donors of all types of organs since at least 2000. Only the recipient need be a customer of the insurer, not the donor.

[UnitedHealthcare](#) began providing a travel and lodging benefit for expenses of people who are donating kidneys to customers of the insurer since 2017. Such expenses are funded up to \$5,000 — regardless of whether the donor is covered by the insurer —



Initiatives For Reducing Financial Disincentives For Living Donation

Tax Deduction or Credits

- 19 states have enacted tax deductions or credits to living donors.
- Up to \$10,000 for Organ Donation
 - Tax Deduction or Tax Credit:
 - A taxpayer may take a tax deduction or tax credit to cover the unreimbursed cost of travel, lodging, lost wages, and medical expenses for organ or bone marrow donation.

Initiatives For Reducing Financial Disincentives For Living Donation

Federal Legislation Donor Leave Laws

- **Donor Leave Laws:** Employees of the federal government receive 30 days paid leave for organ donation and 7 days for bone marrow donation. The leave is over and above the employee's sick and annual leave. ([5 U.S.C. 6327](#))
- **Pending Legislation:** The Living Donor Protection Act ([H.R. 4616/S. 2584](#)) The bill clarifies that any living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from donation.

Initiatives For Reducing Financial Disincentives For Living Donation

State Legislation Donor Leave Laws:

- **Donor Leave Laws:** Modeled after federal law (for federal employees), most states including Texas have begun to offer state employees up to 30 days leave (paid or unpaid) for serving as a living organ donor.
- This leave is considered separate from any annual or sick leave already accrued by an employee.
- 12 states and DC (Arkansas, California, Connecticut, Hawaii, Louisiana, Maine, Minnesota, Nebraska, New York, Oregon, South Carolina, and West Virginia) have organ or bone marrow donor leave policies impacting private sector employees.

Initiatives For Reducing Financial Disincentives And Providing Education For Living Donation

Introduced in House (03/01/2017)
Living Donor Protection Act of 2017

1. This bill prohibits discrimination based on an individual's status as a living organ donor in the offering, issuance, cancellation, coverage, price, or any other condition of a life insurance policy, disability insurance policy, or long-term care insurance policy.
2. The Department of Health and Human Services must update public service announcements, websites, and other media regarding live organ donation to educate the public on the benefits of live organ donation and on access to insurance for living organ donors.



Introduced 2016 and 2017 and did not move past the House. Texas did not sponsor.



The Donate Life Texas Registry is only for registering consent for organ, eye and tissue recovery after death, so it is not part of the process for living donation.

Summary

- 25% of the Public is Willing to Donate Organs.
- Barriers to Donation are lack of awareness, financial and insurability before and after donation.

Summary Continued

Initiatives to increase donation include:

- Education on finding a donor
- Education on how to become a donor
- Developing Donor Advocacy programs
- Using Social Media and Websites to reach large groups for need for a Donor



Summary Continued

Initiatives to increase donation include:

- Government and private agencies providing financial assistance
- Insurance plans covering donor out of pocket expenses
- State tax deductions or credits
- Federal, State and Private Donor Paid leave



Summary Continued

Ongoing Needs to Support Living Organ Donors:

- Financial assistance not adequate
- Texas Medicaid not covering living donor transplants
- All States do not have Tax deductions or Credits and there is nothing at the Federal level
- FMLA is not mandatory to include living donors
- Financial support for Education not adequate
- Insurance discrimination of living donors
- No Living donor Registry in Texas for providing education and resources

