



# Advancing Living Donation & Transplantation by Improving Patient Education and Maximizing Resources

## TODAY'S PANELISTS



**Amy Waterman, PhD**

Division Chief, Patient Engagement and Diversity



**Francis Weng, MD, MSCE**

Transplant Nephrologist



**Harvey Mysel**

2-Time Kidney Recipient;  
Founder



**LivingKidney**  
DONORS NETWORK

Tuesday, October 31, 2023, 2:00pm – 3:30pm ET



# Continuing Education Information

## Evaluations & Certificates

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### Nursing

The Organ Donation and Transplantation Alliance is offering **1.0 hours of continuing education credit** for this offering, approved by The California Board of Registered Nursing, Provider Number CEP17117. No partial credits will be awarded. CE credit will be issued upon request within 30 days post-webinar.

### CEPTC

The Organ Donation and Transplantation Alliance will be offering **1.0 Category I CEPTC credits** from the American Board for Transplant Certification. Certified clinical transplant and procurement coordinators and certified clinical transplant nurses seeking CEPTC credit must complete the evaluation form within 30 days of the event.

### Certificate of Attendance

Participants desiring CE's that are not being offered, should complete a certificate of attendance.

- Certificates should be claimed within 30 days of this webinar.
- We highly encourage you to provide us with your feedback through completion of the online evaluation tool.
- Detailed instructions will be emailed to you within the next 24 hours.
- You will receive a certificate via email upon completion of a certificate request or an evaluation
- Group leaders, please share the follow-up email with all group participants who attended the webinar.





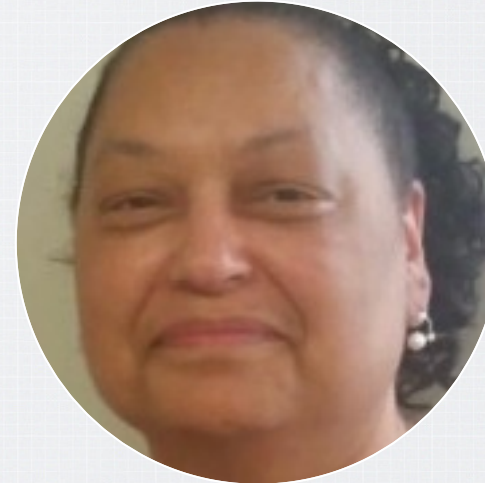
**Deanna Fenton**

Senior Manager, Educational  
Program Development &  
Operations

## Need Assistance?

Contact Us via Zoom Chat, or  
[info@organdonationalliance.org](mailto:info@organdonationalliance.org)  
786-866-8730

# Meet Our Moderator



**Valinda Jones** MSN, RN

Former Transplant Quality Professional;  
Vice President, OPTN Board of Directors  
for Patient and Donor Affairs

*14-Year KPD Living Kidney Donor  
Recipient*

# Meet Our Panelists



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# Advancing Living Donation & Transplantation by Improving Patient Education and Maximizing Resources

**Amy D. Waterman, PhD**

Deborah C. and Clifton B. Phillips Centennial Chair for Clinical Research in Transplant Medicine  
Professor & Director, Patient Engagement, Diversity and Education

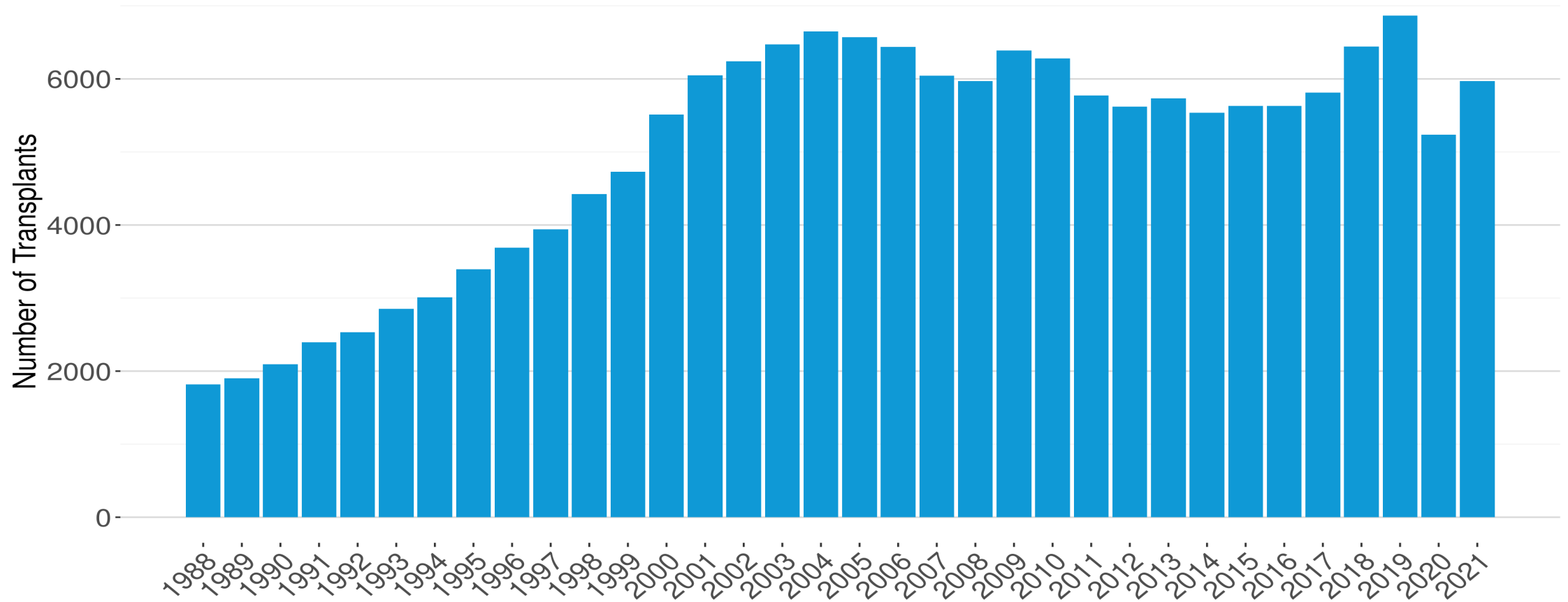


# Learning Objectives

- List the common challenges and barriers associated with living donation, particularly for minority populations.
- Demonstrate an understanding of the various patient readiness stages to effectively determine next steps based on their individual needs and interests.
- Apply lessons learned to develop improved patient education materials and resources to assist patients interested in pursuing living donation, particularly minorities.



# Living donor kidney transplants by year



**UNOS Data:**

5971 living donor kidney transplants were performed in 2021

Up 14% from 2020 (5234 transplants)



# Access to Living Donation by Race/Ethnicity 1995-2014

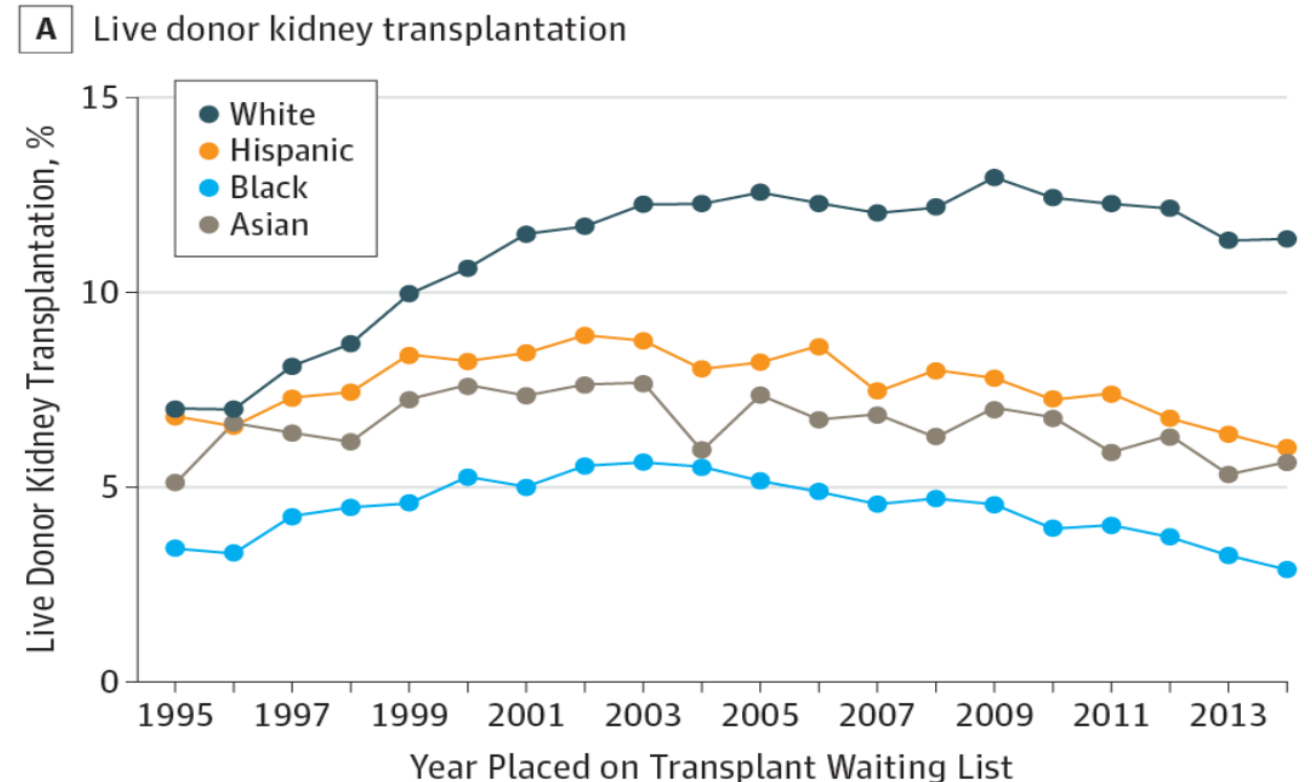
## Association of Race and Ethnicity With Live Donor Kidney Transplantation in the United States From 1995 to 2014

Tanjala S. Purnell, PhD, MPH<sup>1,2,3,4</sup>; Xun Luo, MD, MPH<sup>1</sup>; Lisa A. Cooper, MD, MPH<sup>2,3,4,5</sup>; [et al](#)

» [Author Affiliations](#) | [Article Information](#)

*JAMA*. 2018;319(1):49-61. doi:10.1001/jama.2017.19152

The ongoing increase in disparities in live kidney donor transplantation suggest that national strategies for addressing disparities should be revisited.



# Potential Kidney Recipients

**CJASN** Clinical Journal of the American Society of Nephrology

## **Modifiable Patient Characteristics and Racial Disparities in Evaluation Completion and Living Donor Transplant**

*Amy D. Waterman,\* John D. Peipert,\* Shelley S. Hyland,\* Melanie S. McCabe,\* Emily A. Schenk,\* and Jingxia Liu<sup>†</sup>*

**At Barnes-Jewish Transplant Center, we surveyed 695 White and African-American patients at the start of transplant evaluation and tracked their final transplant outcomes 6 years later.**

# Predictors of Living Donor Transplant

Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant.

**Table 4. Multivariable competing risks model predicting receipt of living donor kidney transplant (*n*=636)**

More-Modifiable Characteristics	HR <sup>a</sup> (95% CI)
Later stages of willingness to allow a living donor to volunteer <sup>b</sup>	4.3 (2.7, 6.8)
Higher transplant knowledge <sup>c</sup>	1.2 (1.1, 1.3)
Race: white	1.2 (0.7, 2.1)








# Possible Living Donation Interventions

## Addressing Disparities in Living Donor Kidney Transplantation A Call to Action

Krista L. Lentine<sup>1</sup> and Didier Mandelbrot<sup>2</sup>  
*Clin J Am Soc Nephrol* 13: 1909–1911,

### Racial Disparities in Access to LDKT

Contributing Factors

-  Lack of knowledge of LDKT benefits
-  Misunderstanding of living donor selection criteria
-  Mistrust of the medical system
-  Financial disincentives to donation
-  Correlation of race and medical comorbidity

### Potential Interventions



Improve culturally tailored education in multiple settings: nephrology and primary care practices, dialysis centers, transplant hospitals



Reduce financial disincentives to living donation

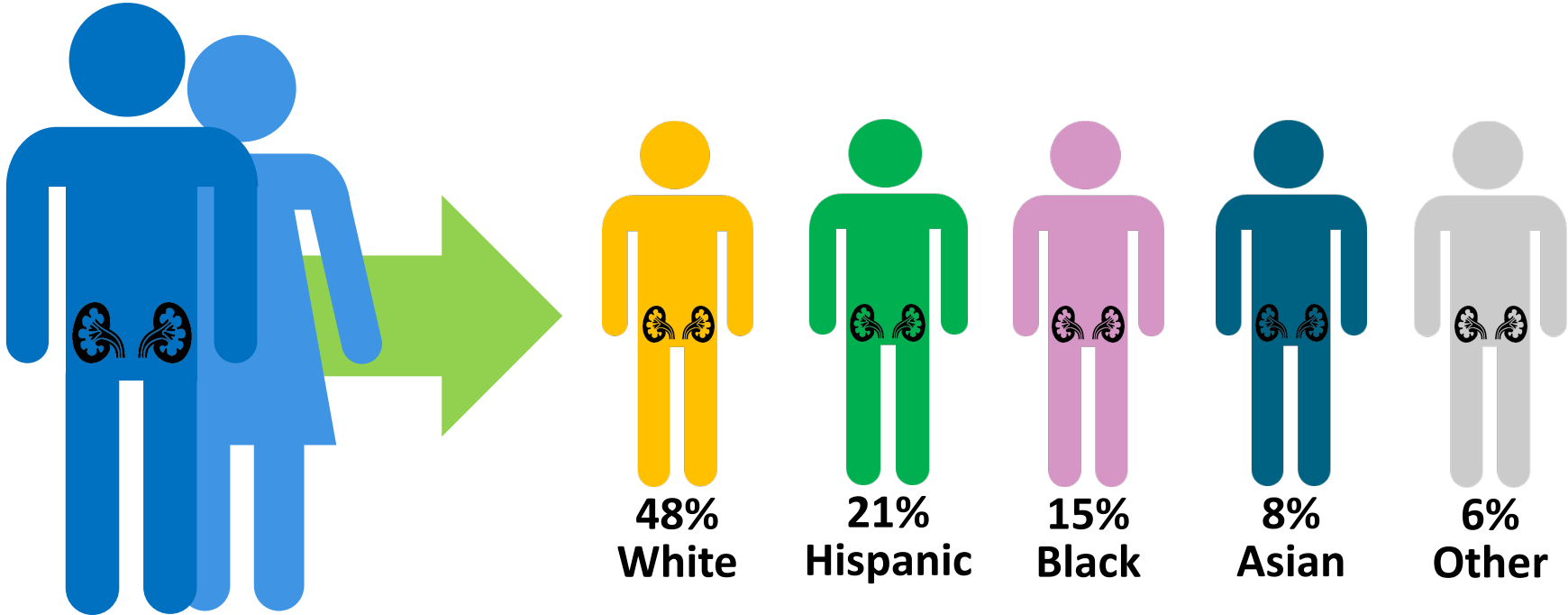


Improve donor risk assessment (inform necessary exclusions; prevent unnecessary exclusions)

May need to find more potential living donors to identify a willing donor with acceptable medical and financial risks



# Potential Living Donors



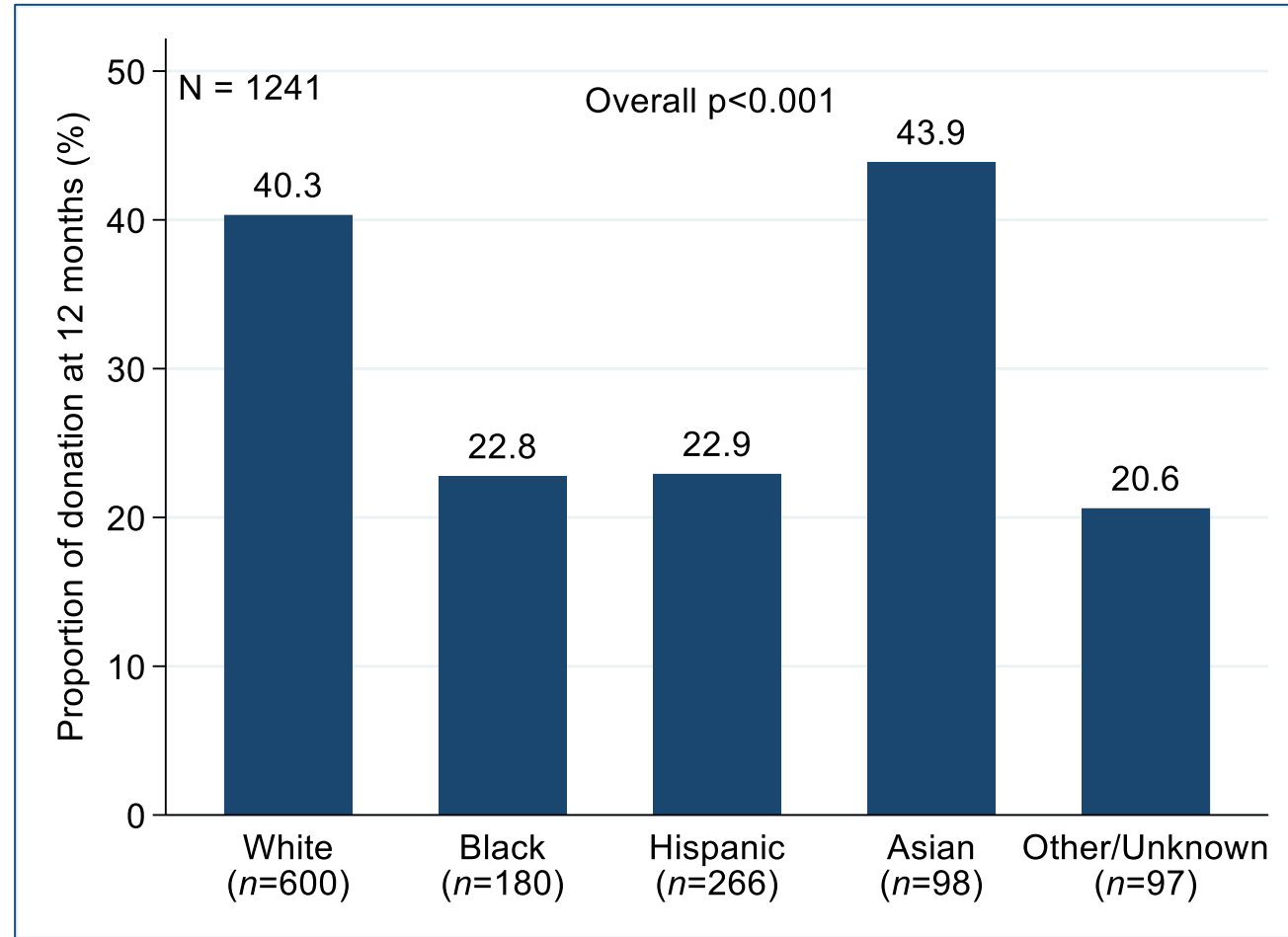
**1241**  
Donors with 12  
months of follow-up

**43 years** of age

**63%** Female

407 Became Living Donors

# Who became actual donors?





# Donor Education is Critical

- Of living donor candidates beginning evaluation at five transplant centers (50% White, 18% Hispanic, 15% Black, and 8% Asian), only **19% donated a kidney within 12 months.**
- Those who donated were more confident in their knowledge about the donation process, more ready to donate, less anxious and had previously discussed donation with their recipient.
- Of the others, **38.2% dropped out or discontinued evaluation for potentially modifiable reasons**, and the remaining 43.2% were ineligible due to medical contraindications.
- Many people are discontinuing evaluation, who, if educated differently, might continue on to actually donate.

# Would you be a living donor?

*"I would not consider being a living kidney donor. I contribute in other ways..."*

*"I would consider donating my kidney to a family member or friend if they were in need"*

*"I would consider donating to anyone because it fits into my humanistic or spiritual worldview"*



# Prochaska's Transtheoretical Model of Behavioral Change (TTM)



*People are in different stages of readiness to take a behavior:*



Precontemplation

Contemplation

Preparation

Action

Maintenance



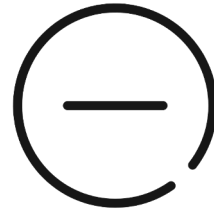
# Precontemplation



I won't do this. I am not ready to do this.



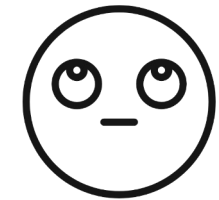
## Indicators



Sees no pros to taking the action, it is not a priority



Doesn't want to talk about it, feels hopeless



May look uncomfortable, resist, or ignore education

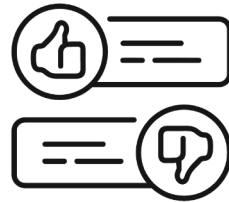
# Contemplation



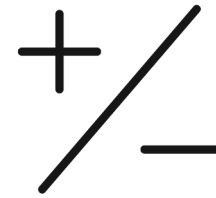
I may do this in the next 6 months. I am thinking a little about it.



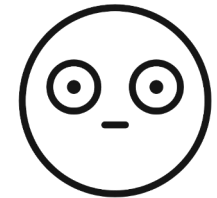
## Indicators



Doing this is a good thing, but...



Sees as many pros as cons



Can stay in this stage indefinitely — no urgency

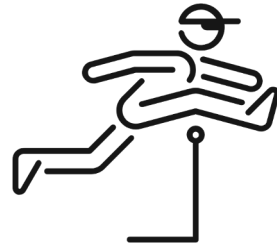
# Preparation



I will do this in one month. I am planning how to do this.



## Indicators



Figuring out how to overcome final barriers



Needs help and support to begin



Hungry for information and discussion

# Action



I am currently doing this.



## Indicators



Thinks doing this is good



Proud of self, excited



Not certain can fully succeed, could slip back

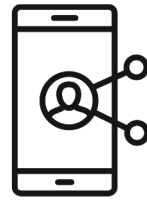
# Maintenance



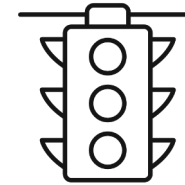
I am already doing this.



## Indicators



Wants to share it with others



Rarely gets stopped by barriers



Wants to learn new tips, not plateau



# Applying Stages of Change to Education

Reduce Pressure, Honor Learning

The end goal is to shift patient one stage by recommending small changes

Stage	Education practices	
Precontemplation	Plant the idea	Gentle support and respect
Contemplation	Shift their ambivalence	Help patient/donor think about the pros and what is important to them
Preparation	Help them begin/continue	Help create a plan to take the next right steps
Action / Maintenance	Support not dropping out	Problem-solve common barriers and celebrate progress



[www.livingdonationstories.org](http://www.livingdonationstories.org)

# Value of Storytelling vs. Education

Gets people curious to learn more

Empowers donors and recipients to talk about the issues that truly matter to them; peer to peer sharing about what is important

Emotionally powerful content vs. just facts

Gentle invitation to learn more for early learners

Culturally grounds the messages and experiences of the target audience. Storytellers can look like viewers.



Each patient or donor  
creates their own video story

## MY DONOR STORY

Please unselect any question you don't feel comfortable answering. If you have any supporting photos, just hold them to the camera before or after you answer a question.

**MY STORY (0 OF 22)**

Say "Hello, my name is (name). I donated a kidney to (recipients i.e., Dad, sister etc)

When I started to learn what kidney failure meant or was like for my (recipient), I was surprised to learn that...

When I started to learn what kidney failure meant or was like for my (recipient), I was surprised to learn that...

I was motivated to donate a kidney because...

When I started to research living donation, the most surprising thing I learned was...

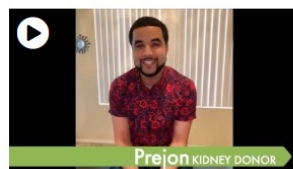
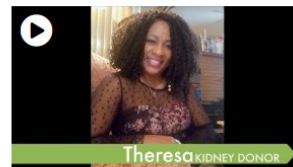
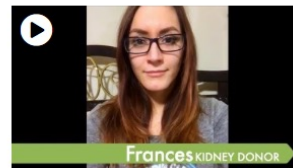
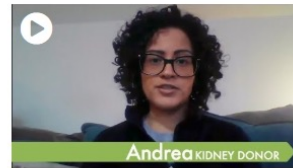
I had many private & personal fears and questions about the process, the main ones were...

# Donor stories

Learn why people donated a kidney and how they feel today. Browse the videos below or search for specific types of stories.

This library keeps growing. Watch the videos we have now and please consider adding your own story.

See results





# Living Donors: Themes Shared

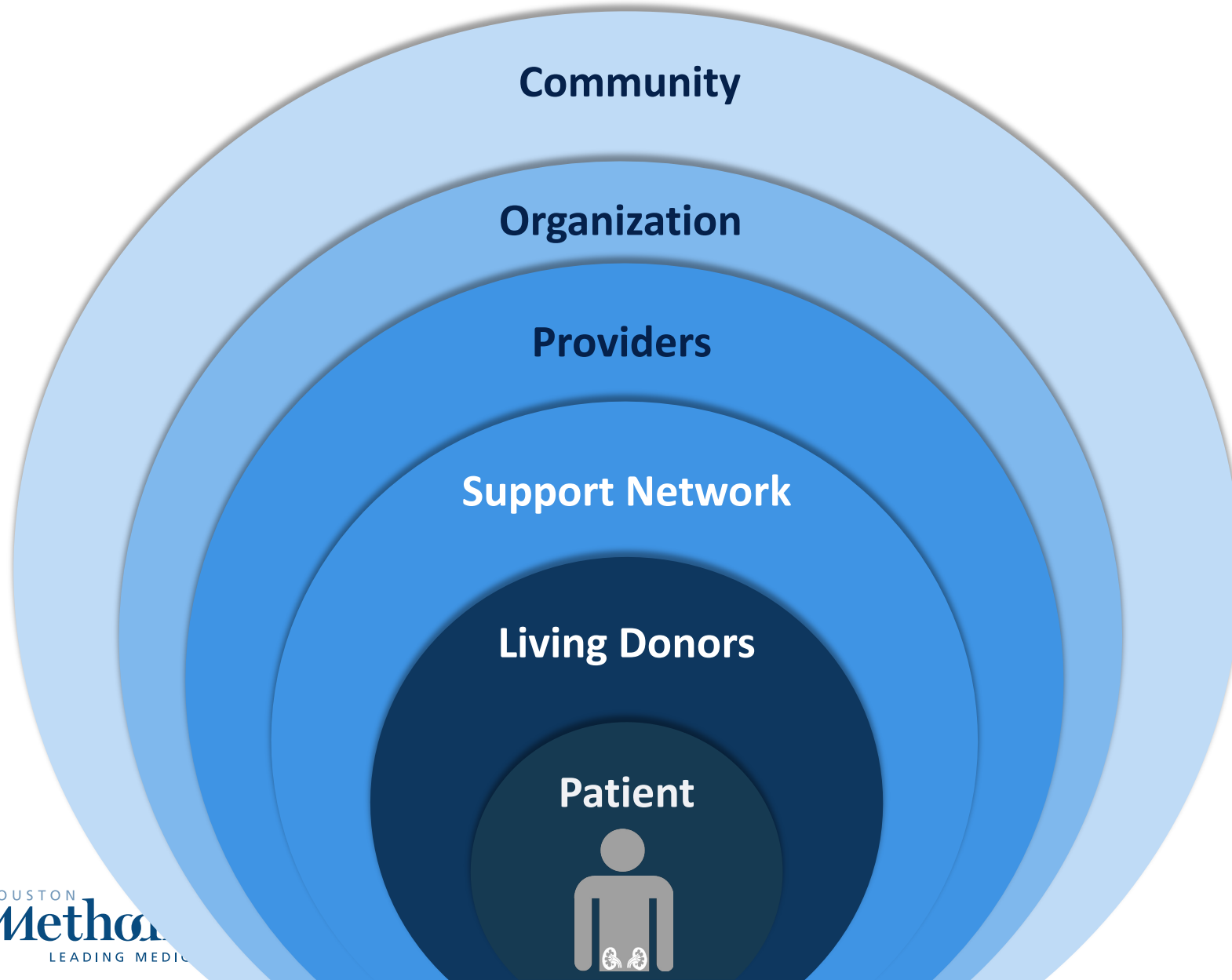
## PRE-DONATION

- Motivations for donating
  - Influenced by faith & helping others
  - Prior knowledge of kidney disease & transplant
  - Save a Life
- Family concern about the donor being harmed
- Fears and challenges experienced during the evaluation process

## POST-DONATION

- Confirmation of decision to donate
- Donors felt happiness
  - Changed a patient's life
  - Recipient's health improved
- Positive life changes
  - More altruistic after donation
  - Improved personal health care
- Reality of recovery (+/-)

# Multilevel Intervention Framework



**Address barriers and facilitators affecting transplant at many levels, at the same time**

**Focus on what is modifiable at all levels**

# Utilizing Technology to Improve Education

Where could we use Health IT education solutions to improve or deepen the patient experience (and make it easier for busy clinicians?)

When is the compassion and care from a clinician or educator essential and irreplaceable for patients? Or for certain patient groups?

How can we build care delivery improvements that incorporate the best of both within our ever-changing healthcare field?

# Assessing Efficacy of Health Literate Resources & Health IT

## 3.1 | Introducing kidney paired donation

Watch this video clip for an introduction to kidney paired donation (KPD).



EXPLORE Transplant & Living Donation

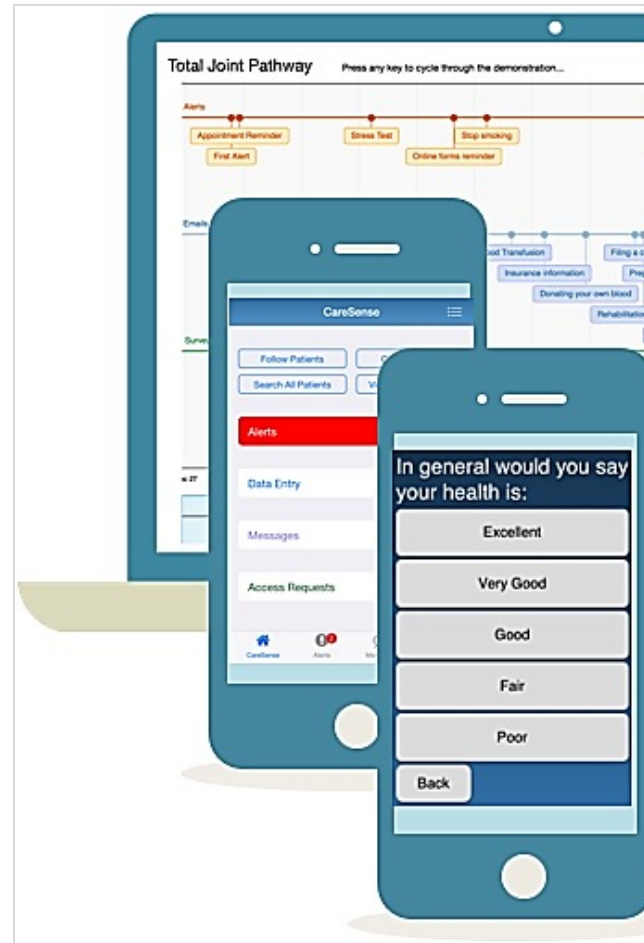
My Transplant & Paired Donation Coach

Chapter 3:

Introducing kidney paired donation



*Transplant Animations*






## Background/Introduction

CareSense is a patient facing communication tool that Houston Methodist uses to clinically monitor and educate patients pre and post procedure or diagnosis.

CARESENSE

# My Transplant Coach

**Benefits of getting a living donor kidney transplant**

-  Get a transplant within a year
-  Kidney is likely to last a long time
-  Surgery can be scheduled at a convenient time



Address "not harming & protecting the donor" early



➤ **Risks of living & paired donation**

➤ **Financial Protections for Donation**

# Ensure Cultural Competency of Educational Resources – *Hispanic Transplant Program*

Culturally competent transplant program improves Hispanics' knowledge and attitudes about live kidney donation and transplant

Elisa J Gordon <sup>1</sup>, Elizabeth Reddy <sup>2</sup>, Sorelly Gil <sup>1</sup>, Joseph Feinglass <sup>1</sup>, Jillian Rodde <sup>1</sup>, Michael M Abecassis <sup>1</sup>, Juan Carlos Caicedo <sup>1</sup>

**Conclusions:** The educational sessions provided by the Hispanic Transplant Program effectively addressed commonly shared Hispanic concerns about live kidney donation. Culturally congruent education increased Hispanic patients' and family members' knowledge and improved attitudes about live donor kidney transplants.

Culturally competent education program included bilingual transplant team members, print education in Spanish, Spanish spoken during interactions, medical records indicating preferred language, and collaboration of clinicians and specialists who understand Hispanic patient-specific needs

# Support Families, Potential Donors, and Caregivers

CLINICAL AND TRANSLATIONAL RESEARCH

## Making House Calls Increases Living Donor Inquiries and Evaluations for Blacks on the Kidney Transplant Waiting List

*James R. Rodrigue,<sup>1,5</sup> Matthew J. Paek,<sup>1</sup> Ogo Egbuna,<sup>2</sup> Amy D. Waterman,<sup>3</sup> Jesse D. Schold,<sup>4</sup>  
Martha Pavlakis,<sup>1</sup> and Didier A. Mandelbrot<sup>1</sup>*

**House call intervention: Patient-invited family and friends (potential donors) to their own home where they were visited by a health educator who delivered a 60-90 minute session supplemented with video and print materials, and led a discussion of LDKT**

**Results showed that patients who received a house call were more likely to have at least one donor inquiry and evaluation compared to group-based and individually counselled patients.**

# Screen for need for financial protections early

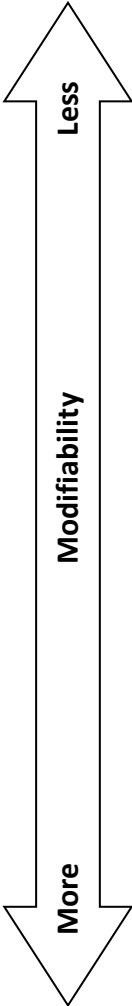
## NKR Donor Shield:

- Travel, lodging, and lost-wage reimbursement
- Does not require recipient financial eligibility criteria.
- Kidney and liver living donors are eligible.
- Receive quick reimbursement after evaluation or donation.

## The National Living Donor Assistance Program (NLDAC):

- Evaluation, travel, lodging and lost-wage reimbursement
- Prioritizes people who could not otherwise afford to donate, so requires a financial eligibility screening of recipient.
- Kidney, liver, uterus, intestine and lung living donors are eligible.
- Receive a prepaid credit card so no out of pocket expenses are accrued.

# Areas of Opportunity for Expanded Education

	Patient	Donor	Transplant Center
	Demographics	Demographics	Amount of funding for staff and program costs related to transplant
	SES, Insurance Status	Contraindications to donation	Living and Paired Donation Champions at the leadership level
	Etiology of ESRD	Psychological health of donors	Kidney paired donation transplant center access
	Medical Comorbidities	SES, Insurance Status	Having dedicated donor/paired donation coordinators
	Perceived Health Status	Proximity to Transplant Center	Limited applications to donor financial protection programs
	Time on dialysis before transplant	Size of social support community without contraindications to donation	Having a patient/donor education program built for patients in early readiness
	Psychological health	Family unawareness that living donation is a possibility	Having a donor/recipient peer mentor program
	Proximity to transplant center	Difficulty taking off work for donation	Using technology to deliver a variety of educational resources
	Burden of Kidney Disease	Difficulty covering out of pocket costs	
	Medical Mistrust	Poor knowledge of the benefits of living donation	
	No transplant education received prior to evaluation onset	High Medical Mistrust/Fear about living donation	
	Poor knowledge of benefits of living or paired donation	Lack of understanding or fear of paired donation	
Discomfort asking/sharing information with donor candidates			
Unwillingness to allow a living donor to donate			



# Resources

## Education Resources:

Living Donation Storytelling Project - <https://livingdonationstories.org/>

My Transplant Coach - <https://mytransplantcoach.org/#/>

## Peer Mentor Programs:

NKR National Kidney Donor Organization (NKDO) - <https://www.nkdo.org/>

NKF PEERs Program - <https://www.kidney.org/peers>

## Donor Financial Protection Programs:

National Living Donor Assistance Center - <https://www.livingdonorassistance.org/>

NKR Donor Shield - <https://www.donor-shield.org/>

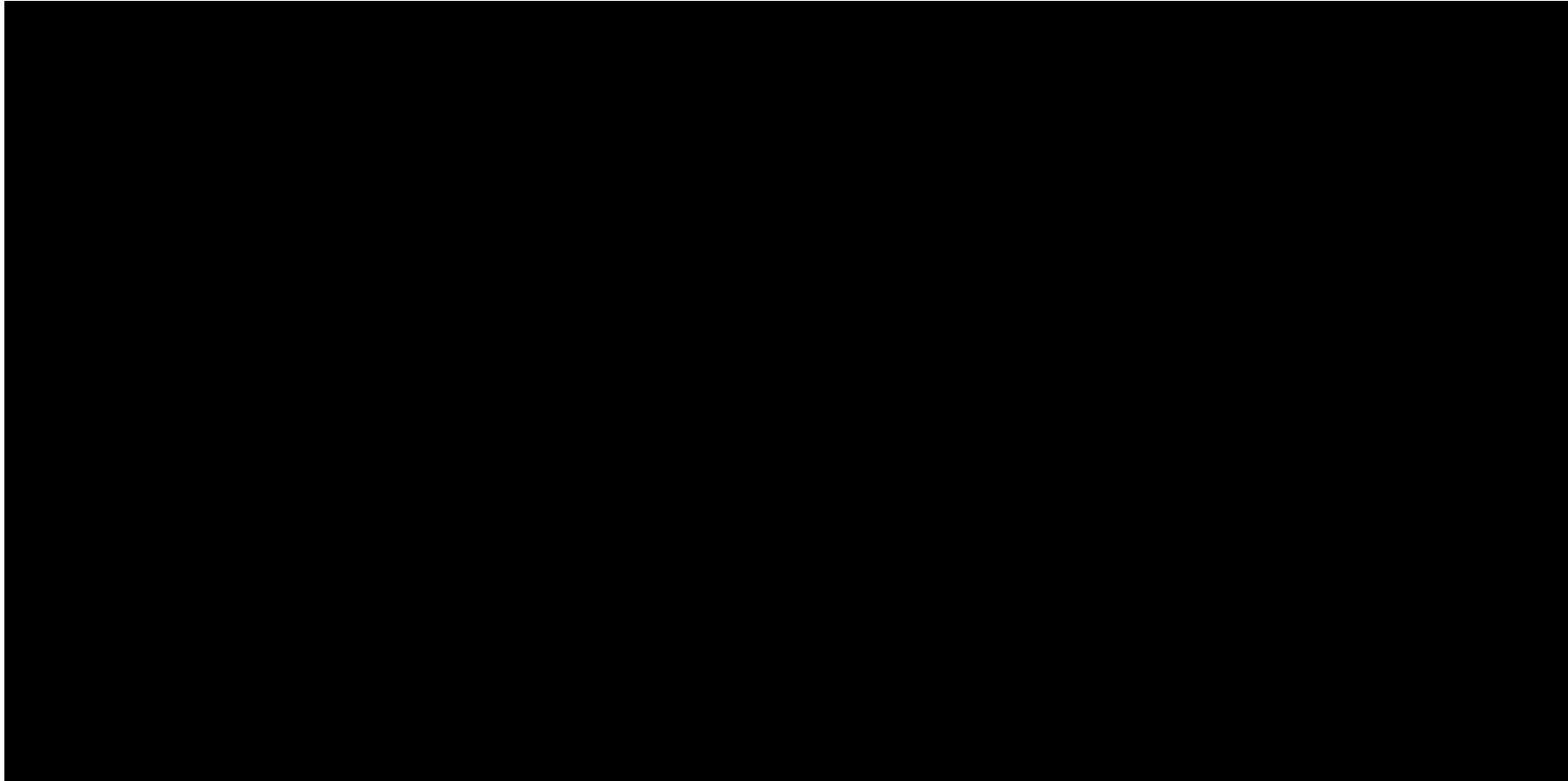
**Questions:** Amy D. Waterman, PhD, [awaterman@houstonmethodist.org](mailto:awaterman@houstonmethodist.org)



**Having Your Kidney Donor Find YOU!**

Having Your Donor Find YOU!

[www.havingyourkidney  
donorfindyou.org](http://www.havingyourkidneydonorfindyou.org)



# Power and Importance of Communication



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We are hardwired for stories

# Communicating Your Need

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**NOT asking someone to donate**



# Communicating Your Need

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**COMMIT to ACTIVELY Develop Your**

**CAMPAIGN**

# Similar Experience – Job Hunting

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- Reality of your Situation – Develop a Plan
- Research Options
- Learn about those Options
- Write out Your Story (*Write a Resume*)
- Networking (*Rock Star in an Elevator*)
- Tell Your Story (*Like a Job Interview*)

## Use Bullets Instead of Paragraphs

### I Need a Kidney Transplant:

- A kidney from a living donor is my best option
- Wait for a deceased donor is 2 -5 years
- Kidney from a living donor lasts...
- I need to avoid or stop dialysis
- I want to....

- Often make the donor/recipient connection
- The Best Advocate is...

# Who To Tell Your Story To

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- **Family Members & Friends**
  - Write out your story
  - Include contact info for the Donor Advocate
  - Include a photo or video
  - Local Media, Schools, Religious Groups, Reunions
  - [www.google.com/alerts](http://www.google.com/alerts)
  - Home Get together

# Who To Tell Your Story To

---

- **Email & Social Media etc.**
  - Email, Facebook Twitter etc.
  - How Often Should I Send an Email or Post?
  - Tuesdays with...update
  - Facebook page & website



# Who To Tell Your Story To


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- **Meeting People Every Day**
  - Hi Harvey, how are you?
  - It's an Everyday life Experience
  - Short lived opportunity
  - Practice!


# Who To Tell Your Story To

---

- **Getting Creative**



Life Donated...Multiplies Life



**Harvey Mysel**  
312-473-3772  
harvey@LKDN.org  
www.harveyskidneykampaign.com

I have kidney disease and in need of a kidney transplant. The wait for a deceased donor kidney can be more than 5 years. I'm actively pursuing a kidney from a living donor. Kidneys from living donors can last twice as long as one from a deceased donor.

Someone in good health, i.e. no uncontrolled hypertension, diabetes etc. is able to donate.

To learn more about my situation contact me or visit the website:  
**harveyskidneykampaign.com** You could also call Jami Hanneman, 312-695-0828 the donor transplant coordinator at Northwestern Memorial Hospital.

Thank you,  
**Harvey**

www.facebook.com/  
LivingKidneyDonorsNetwork







# Standing on a Busy Corner







# Sign in Front of House



**4FredAKidney.com**



Visit [4FredAKidney.com](http://4FredAKidney.com) And Please Read My  
Open Letter To Save My Life And [How You Can Share The Post.](#)

CALL RENEWAL **718-431-9831 x209**  
Fred Howe - Patient ID is "R1044"

All Inquires to Renewal are strictly Confidential and without obligation

 Renewal [www.renewal.org](http://www.renewal.org)

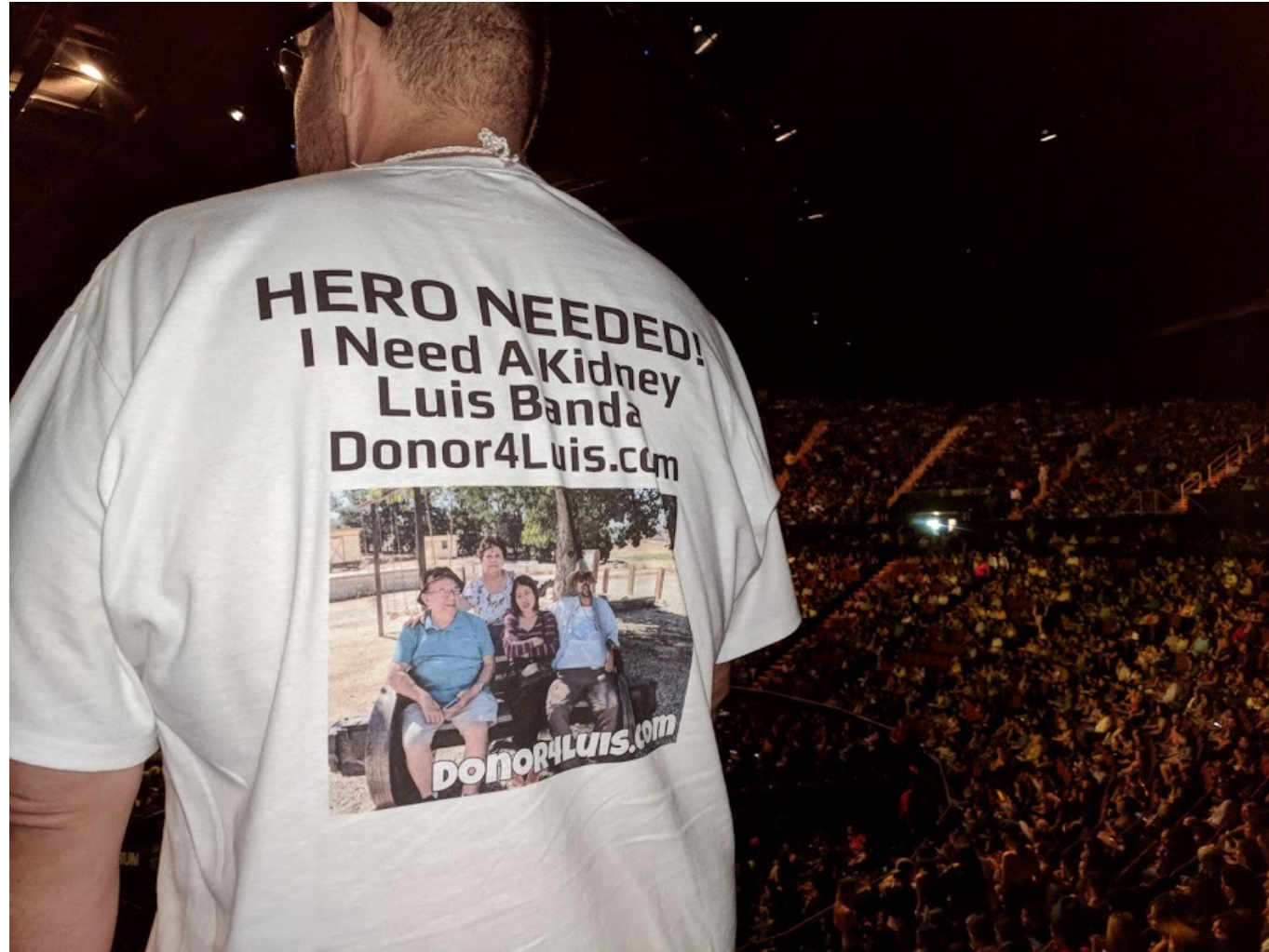


# Sign in Front of House

















# Creative Lawn Sign

<https://www.woodtv.com/news/kent-county/sign-asking-for-kidney-works-got-one/>









# This is Too!

[https://www.youtube.com/watch?v=LQPJyY\\_IZzw](https://www.youtube.com/watch?v=LQPJyY_IZzw)



## Craigslist Ads

Search: *“Craigslist ad I need a kidney transplant”*

# No Need To Share Your Blood Type

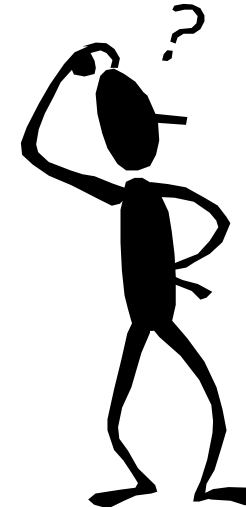
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- Many don't know their blood type
- Others are mistaken about theirs
- Paired Exchanges

## Top Three Takeaways:

- Learn as Much as you can about Living Donation
- Find Advocates – Friends and Family Members
- **Tell Everyone About Your Situation!**

Q & A?







**Harvey Mysel**  
Living Kidney Donors Network  
*a Nonprofit Organization*

[www.LKDN.org](http://www.LKDN.org)  
[harvey@LKDN.org](mailto:harvey@LKDN.org)  
**312-473-3772**

# A Special Thanks to Our Panelists



**Amy Waterman, PhD**

Division Chief, Patient Engagement and Diversity



**Francis Weng, MD, MSCE**

Transplant Nephrologist



**Harvey Mysel**

2-Time Kidney Recipient; Founder





THE  
**Alliance**

Conversation Series

DIVERSITY, EQUITY, AND INCLUSION

FOCUS