



## Expanding Living Donor Transplantation Through Improved Education



Amy D. Waterman, PhD  
Associate Professor of Medicine in Residence  
Nephrology



Hello, From The Tower Building!

→  
12<sup>th</sup> Flr,  
Suite 1223



## Talk Objectives

- Introduce my research team & approach.
- Assess why deceased and living donor transplants aren't always occurring.
- Evaluate the effectiveness of Explore Transplant education on helping dialysis providers become motivated to educate their own patients about transplant and on their patients' living donation rates.
- Discuss how improved transplant education may help more African-American patients learn more about transplant & receive living donor transplants.
- Discuss the possibilities for an Center of Transplant Education and Living Donation.

## Background

- Social/Health Psychologist
- Faculty Member at Washington Univ. School of Medicine, Health Services Research Division
- Quality Manager, Barnes-Jewish Transplant Center
- Founder of Explore Transplant, a Nonprofit Corporation

*Mission: "to increase informed transplant decision-making to promote the highest possible quality-of-life for patients and improve access to transplant education in underserved communities."*



## Research as an Academic Ladder



- A Rigorous Climb
- What I Produce
- Others are competing
- One Way (Up) to Success
- One Leader
- Precarious
- Fixed



## Research as a Jungle Gym



- Climbing as Play
- What We Produce
- Others are Collaborative
- Multiple paths to success
- Move in many directions
- Stable
- Creative

-Sheryl Sandburg, Lean In



## My Jungle Gym

<b>Grant Funding</b>	<ul style="list-style-type: none"><li>■ NIH, NIDDK</li><li>■ HRSA</li><li>■ OneLegacy Foundation</li></ul>
<b>Research Team</b>	<ul style="list-style-type: none"><li>■ Christina Goalby, MSW</li><li>■ Crystal Kynard-Amerson, MPH</li><li>■ Anna-Michelle McSorley, BA</li><li>■ John (Devin) Peipert, MA</li><li>■ Riya Rajan, BA</li><li>■ Jessica Thein, BA</li></ul>
<b>Advisory Board</b>	Representatives of ESRD Networks, UNOS, Dialysis, Transplant Centers, and OPOs, Kidney Patients & Living Donors

## Research Collaborators, So Far

<b>Research Collaborators</b>	<ul style="list-style-type: none"><li>■ Mark Robbins, PhD &amp; Andrea Paiva, PhD <i>University of Rhode Island</i></li><li>■ Alan Leichtman, MD <i>University of Michigan</i></li><li>■ Francis Weng, MD, MSCE <i>St. Barnabas Transplant Center</i></li><li>■ Timothy McBride, PhD <i>Washington University School of Medicine</i></li><li>■ Osama Gaber, MD <i>Methodist Houston Transplant Center</i></li><li>■ Keith Norris, MD, PhD, Jeffrey Veale, MD, Eric Treat, MD <i>David Geffen School of Medicine, UCLA</i></li></ul>
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## Why Transplant, Anyway?

- Best of humanity, best of healthcare.
- We can intervene to reduce or solve this healthcare problem – “the need for organs for transplant.”
- Allows the work of a Social Psychologist to improve health and sustain lives.

## Research Mission

- To develop, assess the effectiveness of, and nationally disseminate patient and provider education that improves informed transplant and living donation decision-making, care, and outcomes.
- To reduce racial disparities in access to transplant and living donation.
- To increase living donation rates.

*...To solve the shortage of donated organs!*

## Dialysis & Kidney Transplant

### Dialysis Population:

- 594,000 patients with kidney failure<sup>1</sup>
- 415,000 (70%) on dialysis<sup>1</sup>
- 96,000 candidates on the transplant waiting list<sup>2</sup>

### Dialysis Patients of color are less likely:

- To be referred for transplant evaluation<sup>3</sup>
- To receive deceased or living donor transplants<sup>4</sup>

**So, are dialysis patients  
who are not pursuing transplant uninterested  
or unaware of the option?**

<sup>1</sup>USRDS (2012) Atlas; <sup>2</sup>OPTN data as of 05/10/2013; <sup>3</sup>Alexander & Sehgal (1998) JAMA 280(13):1148-1152.  
<sup>4</sup>Epstein, et al. (2000) N Engl J Med 343(21):1537-1544

## Road to Transplant Requires:

- Learn about transplant as an option
- Call to begin evaluation
- Mail medical packet
- Attend transplant appointments
- Get listed for transplant
- Complete yearly re-evaluation
- Find a matching kidney
- Receive a deceased or living donor transplant



## Road to Transplant

- ▶ Learn about transplant as an option
- ▶ Call to begin evaluation
- ▶ Mail medical packet
  - Attend transplant appointments
  - Get listed for transplant
  - Complete yearly re-evaluation
  - Find a matching kidney
  - Receive a deceased or living donor transplant



## Transplant Study: 2004-2010

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

- 27% received a deceased donor kidney transplant (DDKT)
- 18% received a living donor kidney transplant (LDKT).
- Fewer Black patients received a LDKT compared with Whites (9% vs. 22%,  $p < .001$ )

We measured less- and more-modifiable variables to determine what predicted successful completion of evaluation and LDKT.

<sup>1</sup>Waterman, et al. *Clin J Am Soc Nephrol*; Mar 21 2013.



## Transplant Study: 2004-2010

At the beginning of evaluation, patients who:

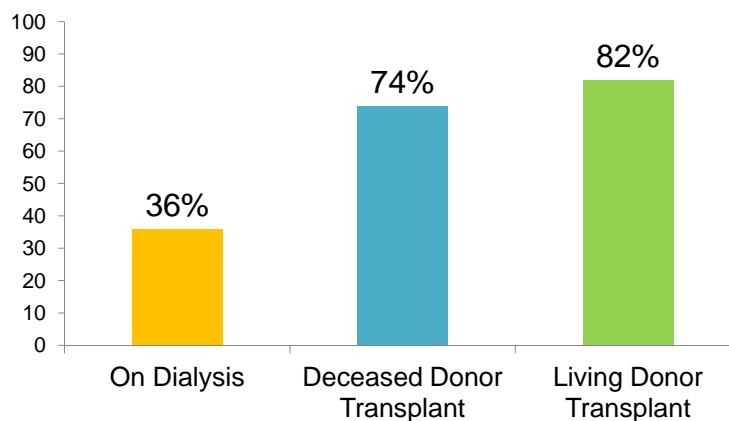
- had received better education from community nephrologists/in dialysis centers
- were more knowledgeable about transplant
- were more motivated to pursue DDKT and LDKT

...were 2 to 3 times more likely to complete transplant evaluation successfully and receive LDKTs six years later.

<sup>1</sup>Waterman, et al. *Clin J Am Soc Nephrol*; Mar 21 2013.



## 5-Year Life Expectancy: Dialysis vs. Transplant



USRDS Annual Report 2012





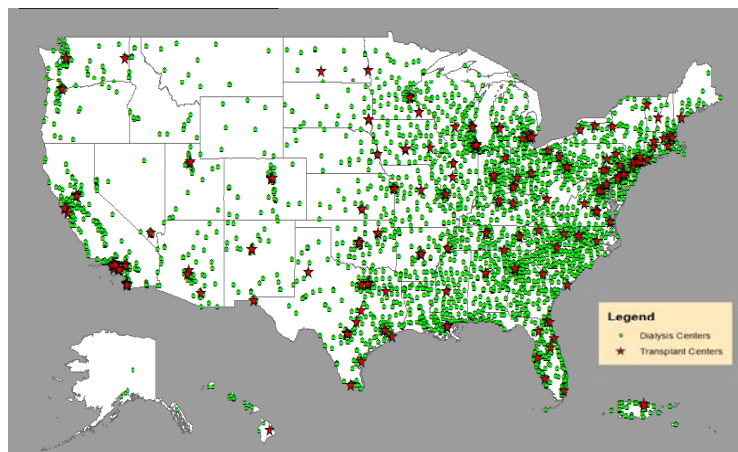
## CMS Conditions for Coverage for Dialysis Facilities

US Dialysis Centers must:

- Provide evidence of transplant education (V458, V554)
- Track patients' transplant referrals and their status on wait list (V561)
- Communicate with transplant facilities regarding patient status annually and when there is a change in transplant status (V561)



## 6000 Dialysis and 250 Transplant Centers



## What Transplant Education is Happening?

Surveyed 1544 dialysis providers from 1035 dialysis centers to learn:

- Attitudes about educating about transplant
- Transplant knowledge levels
- Transplant educational practices



## Transplant Education Attitudes

55%

Were **dissatisfied** with currently available transplant education materials

53%

Were **not confident** in their ability to be a transplant educator

27%

Perceived communication between dialysis and transplant centers to be **poor**



## Poor Dialysis Provider Knowledge About Transplant

	% Correct of 16 Questions (N=1544)
A living donor kidney lasts 15-20 years, on average.	19%
Dialysis is equivalent to the work of 10-15% of one functioning kidney.	23%
Living donors have a risk of high blood pressure after donating.	27%
90% of transplanted kidneys function for at least 1 year.	41%
<b>Transplant Knowledge</b>	<b>42%</b>

## Transplant Education Practices in Dialysis Centers

	Providers engaging in this practice: (N=1544)
Orally recommend patients learn more about transplant themselves	72%
Orally recommend being evaluated for transplant	69%
Refer patients to an external transplant educational program	44%
Distribute transplant center phone numbers	37%
Detailed discussion about advantages/risks of DDKT	21%
Detailed discussion about advantages/risks of LDKT	21%

## How Can We Help Dialysis Providers Better Educate about Transplant?



## Partnerships with 8 ESRD Networks overseeing care of 150,000 Patients

**The National  
FORUM of  
ESRD NETWORKS**  
Improving Care Through Collaboration



Network #15  
**InterMountain ESRD Network, Inc.**

**The Renal Network, Inc.**  
ESRD Networks 4, 9 & 10

End Stage Renal Disease  
**Network of New England**



  
Western Pacific Renal Network, LLC.



## National Quality Improvement Initiative

Conduct Dialysis Provider Trainings to better prepare dialysis providers to educate their own patients about transplant.



## During the Training

Peer-to-peer discussions about:

- Barriers to transplant education in dialysis centers
- What transplant education approaches might help



## During the Training

Videos, exercises, and training demonstrating how to use Explore Transplant education with patients



## During the Training

Expert Panel discussing:

- Being a Kidney Recipient or Living Donor
- Risks/benefits, out-of-pocket costs associated with transplant, living donation



## After Completing This Training



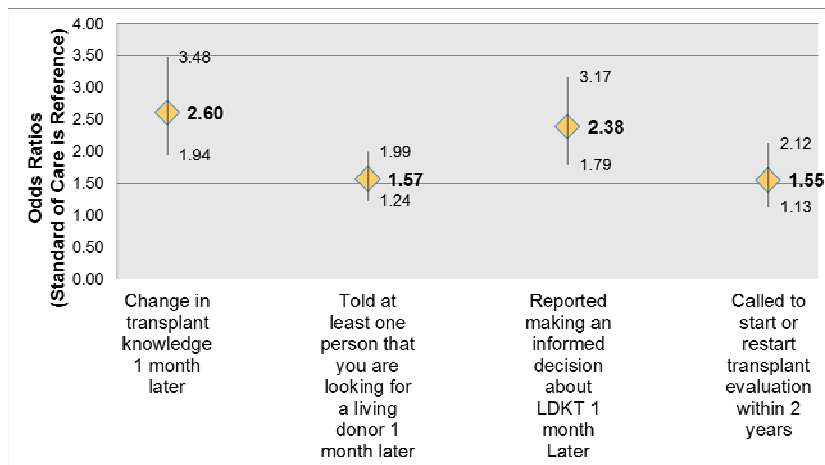
## What is Explore Transplant?

- Comprehensive education program that **helps kidney patients make informed transplant decisions**
  - Video, print resources with patient and donor stories
  - Discussion of risks/benefits of transplant and living donation
- Individually-tailored conversations based on what is important to patient
- Educational materials for dialysis patients, family members & living donors





## cRCT: Impact of Explore Transplant



†All statistical tests accounted for dialysis center clustering.

## Goal: Train an Army of Dialysis Providers as Transplant Educators

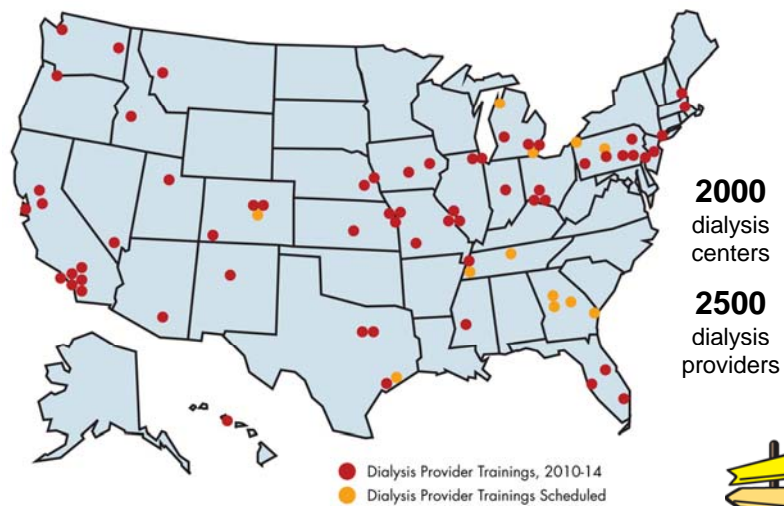




**Goal: Generate Transplant & Living Donation Discussion Within Families**



**65 Explore Transplant Trainings to Date**



## Regional and National Transplant Education Data

2009-  
2011

11 Trainings with Heartland Kidney Network

257 providers trained, 199 dialysis centers  
(73% RR)

Six-month provider & two-year center follow-up complete

2011-  
2013

32 Trainings sponsored by multiple Networks and organizations

1544 providers trained, 1035 dialysis centers

Follow-up ongoing

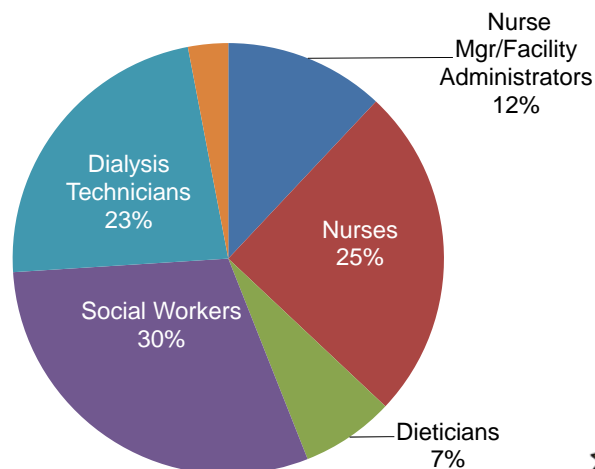


## Outcomes Assessed

- Post-training (national data)
  - Changes in providers' transplant knowledge & confidence educating
  - Transplant Education Action Plans
- Six months later (regional data)
  - Number of education packets disseminated
  - Actual transplant education practices
- Two years later (regional data)
  - LDKT rates at dialysis center level



## Who Attended Trainings?



N=1544

## Transplant Attitude Change

	Before Training (% Agree)	After Training (% Agree)
I am sufficiently knowledgeable about transplant that I could answer most patients' questions.*	46%	82%
I am confident in my ability as a transplant educator.	41%	77%
The transplant education materials available at my dialysis center are excellent.*	39%	69%

\*p<.001; N=1544

## Transplant Knowledge Change

	Before Training (% Correct)	After Training (% Correct)
A living donor kidney lasts 15-20 years, on average.*	19%	86%
Dialysis is equivalent to the work of 10-15% of one functioning kidney.*	23%	82%
Living donors have a risk of high blood pressure after donating.*	27%	87%
90% of transplanted kidneys function for at least 1 year.*	41%	92%
<b>Overall Knowledge*</b>	<b>42%</b>	<b>92%</b>

\*p<.001, N=1544

## Explore Transplant Action Plans

	Already done or planning to do (N=1544)	Completed six months later (N=601)
<i>After the training, do you plan to:</i>		
Determine which patients are on the waiting list?	88%	<b>85%</b>
Determine which patients are transplant candidates?	87%	<b>75%</b>
Hang Explore Transplant posters in your dialysis center waiting room?	86%	<b>54%</b>
Share Explore Transplant materials and videos with your dialysis team?	85%	<b>44%</b>

N=1544

## Post-Training Planned & Actual Education Actions

	% planned to do within 1-6 months (N=1544)	Took action 6 months later (N=601)
Educate at least 1 patient using <i>Explore Transplant</i>	84%	34%
Educate at least 5 patients...	75%	25%



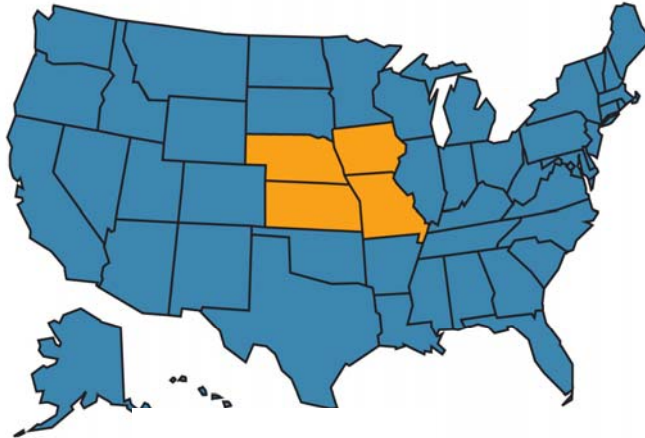
## Explore Transplant Education Packets Disseminated

English	Spanish	Total
10,698	3,635	14,333



N=1544

## The Heartland Kidney Network



The Heartland Kidney Network (ESRD Network 12) oversees quality of care for 14,000 patients in 274 centers



## Explore Transplant In Action

Marianne used Explore Transplant, and in the first six months:

Patients who...	of 14 dialysis patients educated
Are currently being evaluated	5
Identified donors and approved for transplant	2
Received a living donor transplant	2
Were evaluated, medically ruled out	1
<b>Total Patients Who Initiated Transplant Evaluation</b>	<b>10</b>



## Predictors of Having $\geq 1$ Living Donor Transplant in 2010 & 2011

Dialysis Center Level Data	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Provider reported educating $\geq 5$ patients using ET (yes/no)	1.37 (1.03, 1.81)*	1.32 (1.01, 1.74)*
Center located in urban area (yes/no)	1.65 (1.33, 2.04)**	1.63 (1.32, 2.02)**
For-profit center (vs. non-profit)	0.88 (0.70, 1.11)	-
Proportion of Patients Age > 65: $\geq 50\%$	0.77 (0.62, 0.95)*	-
Proportion of Black Patients: $\geq 50\%$	0.87 (0.66, 1.15)	-
Proportion of Female Patients: $\geq 50\%$	0.91 (0.70, 1.18)	-

\*p<0.05, \*\*p<0.001

## Next Steps within Dialysis Centers

- Conduct secondary data analyses to understand predictors of dialysis centers having increased transplant rates using Explore Transplant nationally
- Explore transplant education failures and what else is needed (e.g., transplant outreach + Explore Transplant)
- Expand and replicate Explore Transplant research and education program for the Spanish-speaking Latino community



## Patient Education by Phone/Mail: A Health Insurance Education Model

- Use of Explore Transplant varied by dialysis center educator.
- Health Insurance Companies conduct phone/mail interventions to patients with specific ICD-9 codes directly, often using a case manager
- Determine best transplant education practices for use by health insurance companies



## Conducting an RCT of “Explore Transplant at Home”

- Compared to receiving only transplant education within the dialysis center, 675 White and African-American dialysis patients meeting specific lower income criteria will receive:
  - “Explore Transplant at Home.” Guided video program, sequential print mailings, and texting reminders over 8-months (Lower cost)
  - Case-manager facilitated education + “Explore Transplant at Home” program (Higher cost)
- Outcomes: Transplant knowledge change & plan to take different transplant steps





## Road to Transplant: At Transplant Center

- Learn about transplant as an option
- Call to begin evaluation
- Mail medical packet
- ▶ Attend transplant appointments
- ▶ Get listed for transplant
- ▶ Complete yearly re-evaluation
- ▶ Find a matching kidney
- ▶ Receive a deceased or living donor transplant



## National Racial Disparities in Transplant

- African Americans are 3.4 times more likely to have kidney failure than Whites<sup>1</sup>
- Despite this:
  - In 2013, African-Americans received only 25% of all kidney transplants and 13% of all living donor transplants<sup>2</sup>
  - A 2012 study found that there was a disparity in attainment of living donor transplants between African-Americans and non-African-Americans ***in every transplant center in the U.S.***<sup>3</sup>

<sup>1</sup>USRDS, 2013; <sup>2</sup>OPTN, 2/7/2014; <sup>3</sup>Hall et al., 2012



## Racial Disparities in Transplant at UCLA

- In 2013, at UCLA:
  - 1453 patients presented for evaluation
  - 265 total kidney transplants, 110 living donor transplants
  - African-Americans received 11% of all transplants ( $n=30$ )<sup>1</sup>
  - African-Americans only received 4.5% of living donor transplants ( $n=5$ )<sup>1</sup>

<sup>1</sup>OPTN, 2/7/2014



## Educational Trial Targeted to Reduce This Disparity



- Individually-Tailored Education & Coaching for patients pursuing transplant

<sup>1</sup>OPTN, 2/7/2014



## Two-Year Development of a Transplant Expert System



## What is an Expert System?

- An expert system is a computerized database of transplant information; thousands of responses to what patients could know, think, and believe about transplant
- Based on answers to survey questions:
  - A patient can receive individually-tailored feedback.
  - The patient and her provider can focus on what information is most important to learn or do today.
  - Over time, new data can be compared with old data to see how this patient is changing and to make new recommendations.



## Uniqueness of Expert Systems

- Recognizes there is a decision process that happens in stages
- Tailored to the needs of all patients, not just those ready for action
- Targets different variables at each stage
- Can produce 2-3 times more impact than programs focused on the “prepared.”



## R01 Grant Aims

Compared to standard-of-care transplant education, to determine whether African-American and White patients receiving *Your Path to Transplant*:

- Have greater living donation readiness
- Have greater knowledge
- Are taking more living donation action steps
- Complete transplant medical evaluation
- Receive living donor transplants



## Method & Measurement Plan

- 

You have told us  
where you are today...

## Coaching is Critical

### Guided Coaching based on Feedback Report:

- Addresses key transplant and living donation knowledge gaps
- Discusses benefits of getting a transplant and pursuing living donation
- Promotes taking small actions to complete evaluation successfully and pursue living donation
- Celebrates small successes with patient
- Compares current behavior to past behavior to describe how patient has changed on key dimensions

## Focus on Transplant Derailers

Is there anything in your life that could prevent you from successfully completing transplant evaluation?

- Financial instability
- Insufficient childcare coverage
- No access to transportation
- Safety in neighborhood
- Needing more social support than what is available
- Having other stressful events occurring at the same time as evaluation

## If Your Path to Transplant works...

The Expert System could be delivered:

- Online
- At a transplant center while patients wait (e.g. laptop, tablet)
- Via telephone by transplant staff
- Through printed mailed reports to supplement transplant care



## Next Steps in Transplant Centers

- Understand the impact of transplant derailers and develop interventions to overcome them
- Develop new mHealth (phone) interventions
  - Video/Print/Web resources in multiple languages
  - Secure texting initiatives
  - Phone applications for patient and providers
- Develop education to ensure informed decision-making and motivate recipients and donors to participate in chains



## The Status Quo in Education

- Due to the need for living donors, educational initiatives will launch, but they may not truly increase informed decision-making or be maximally effective.
- Individual researchers will explore the effectiveness of different educational approaches, as funding permits.
  - Some educational strategies will work but it will take a long time to know what those are.
- Many healthcare providers will not be having the most effective conversations to increase living donation.
- More patients will die while we all learn, especially minorities.



## What Else is Possible?

### **A Center for Transplant Education and Living Donation at UCLA**

“A Transplant Education Think Tank”





## Center Two-Fold Mission

- *To develop, assess the effectiveness of, and make available state-of-the-art patient, living donor, and provider education about transplantation.*
- *To improve informed transplant and living donation decision-making so that the rates of transplant and living donation nationally are increased.*



## Center for Transplant Education and Living Donation

- Accelerate education development and research on transplant education for all racial/ethnic groups
- Study emerging trends: donor chains, social media, online resources
- Design and test state-of-the-art transplant education resources, including mhealth resources, for patients/living donors
- Conduct secondary data analysis on educational trends in dialysis centers
- Explore transplant policy and economic ramifications of transplant disparities & education gaps.
- Disseminate best practices and education nationally.
- Train providers how to discuss living donation.



## Opportunities

- Become a friend of the Center!
- Provide coaching on the direction of the Center and how it could fit into established research collaborations most successfully.
- Expand or source your research inside of the Center in some way, strengthening ability to obtain grants.
- Help the Center focus in new areas: medication adherence, measurement development, cultural issues affecting health, spirituality, & mhealth design.
- Involve your graduate students, MDs, and PhDs in work happening within Center.



## What This Will Make Possible

- Reduce racial disparities in access to transplant education and transplant
- Ensure informed patient decision-making
- Increase transplant referrals
- Increase living donor transplant rates
- Improve transplant care
- Help more patients live longer with an improved quality-of-life
- Help more families benefit from having these patients living and contributing fully



Thank You...

*...for all you do to help patients!*

Amy D. Waterman, PhD  
awaterman@mednet.ucla.edu  
(314) 322-3880

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



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# R01 Study Design

