

BARRIERS & SOLUTIONS TO INCREASING ORGAN DONATION

THE US PERSPECTIVE

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DISCLOSURES

- I have no disclosures

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OUTLINE

- Basics of organ donation
- Organ donation attitudes and behaviors in the US
- Understanding the disconnect (a.k.a. the "Why Not?")
- Changing the Conversation Part 1: *Community Awareness*
- Changing the Conversation Part 2: *Fundamental Knowledge*
- Ensuring transparency and equity: *Population health and access to transplantation*

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BASICS OF ORGAN DONATION

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WHY DONATE?



More than 1 in 7

15% of US adults are estimated to have chronic kidney disease, that is about 37 million people.

Every 24 hours, **360** people begin dialysis treatment for kidney failure.

In 2018, treating Medicare beneficiaries with CKD cost over **\$81.8 billion**, and treating people with ESRD cost an additional **\$36.6 billion**.

<https://www.cdc.gov/kidneydisease/basics.html>

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WHY DONATE?

- Cirrhosis: 12th leading cause of death in the US
- National cost of treatment: \$14 million to \$2 billion
- Indirect costs: \$10.6 billion
- Liver transplantation is the only effective treatment for end stage liver disease



Gastroenterol Hepatol (N Y). 2011 Oct;7(10):661-71. The current economic burden of cirrhosis. [Guy W.Narf](#), [Christopher W.Duncan](#), [Eugene R.Schiff](#)

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THE NEED IS GREAT

Every **10 Minutes** someone is added to the transplant waiting list

There are **118,098** people in the United States on the waiting lists for organ transplants.

21 people die each day awaiting a transplant

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UP TO 8 LIVES SAVED...

8

AND THERE IS MORE

One donor can...

save up to **8 lives**

through **ORGAN** donation

heal up to **75 lives**

through **TISSUE** donation

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PROCESS OF DONATION

STEP ONE
A patient near death is identified as a potential donor. The hospital medical team continues care until the patient's heart stops beating or brain-death is declared. The patient remains on a ventilator to keep organs healthy.

Hours elapsed: **0:00**

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PROCESS OF DONATION

STEP TWO
The hospital contacts the organ procurement team, which begins monitoring the patient and reviewing medical records.

Hours elapsed: **0:10**

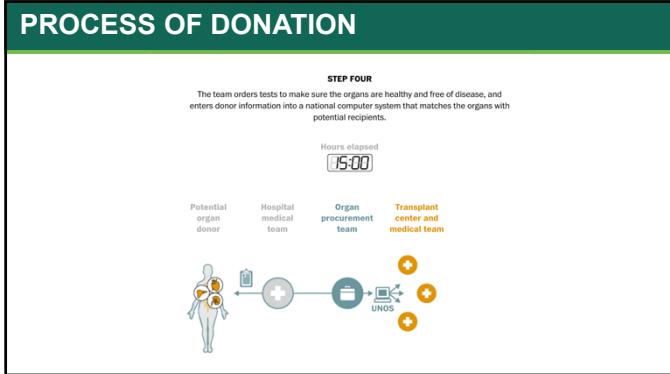
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PROCESS OF DONATION

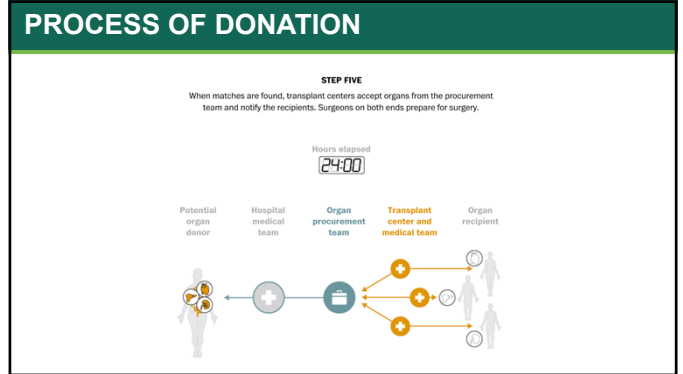
STEP THREE
The procurement team determines whether the patient is a registered organ donor, seeks consent from the family and takes over care of the patient.

Hours elapsed: **0:20**

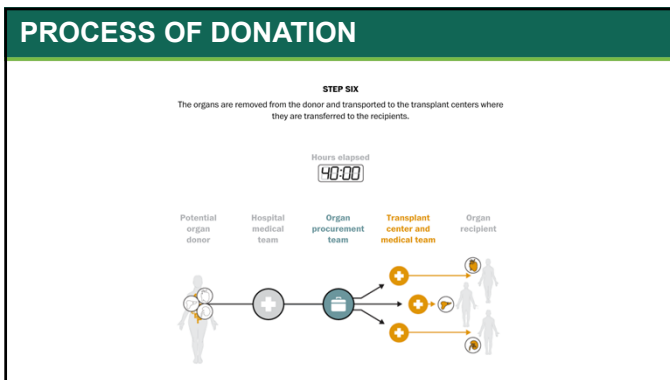
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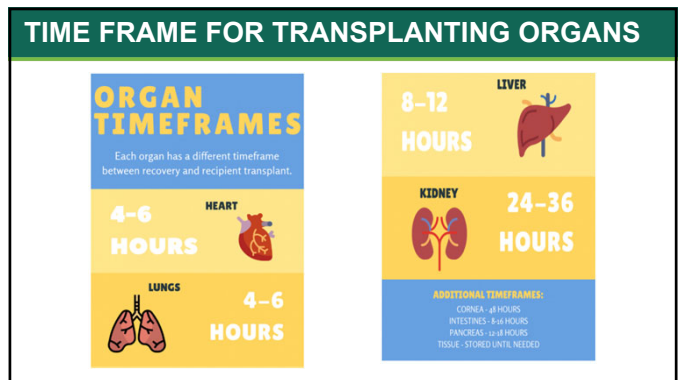
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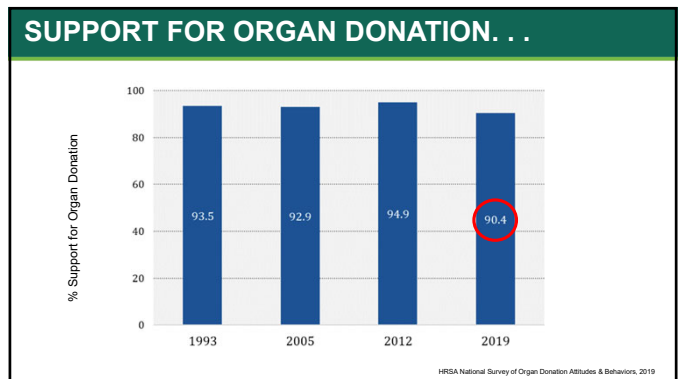
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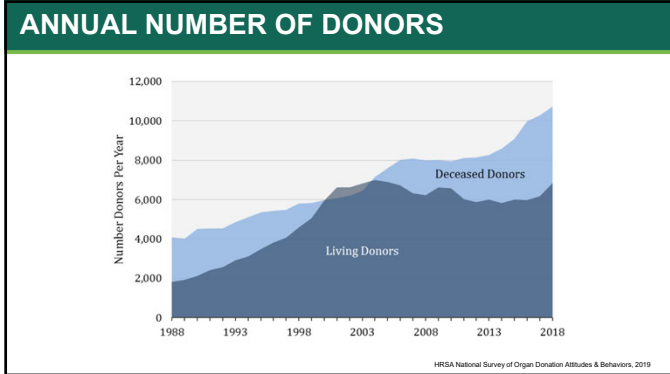
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ATTITUDES AND BEHAVIORS TOWARD ORGAN DONATION

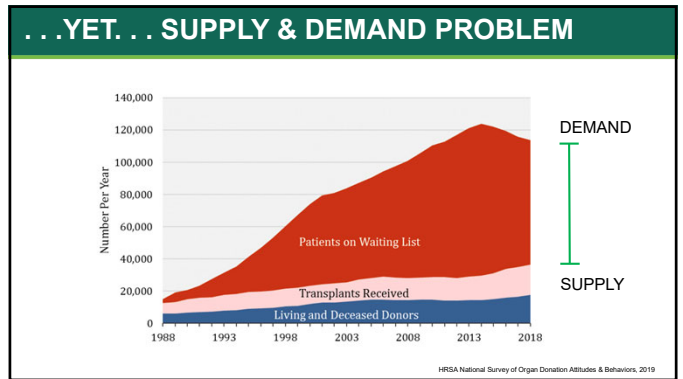
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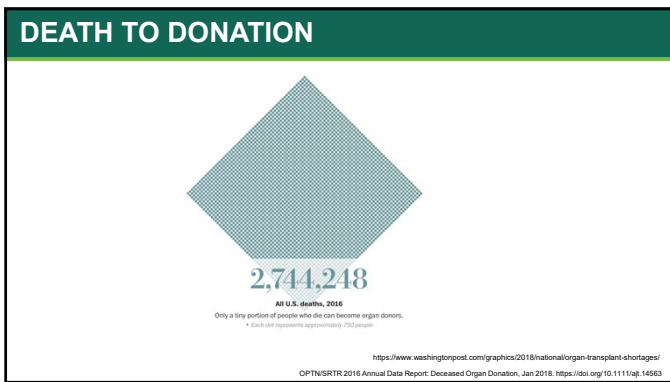
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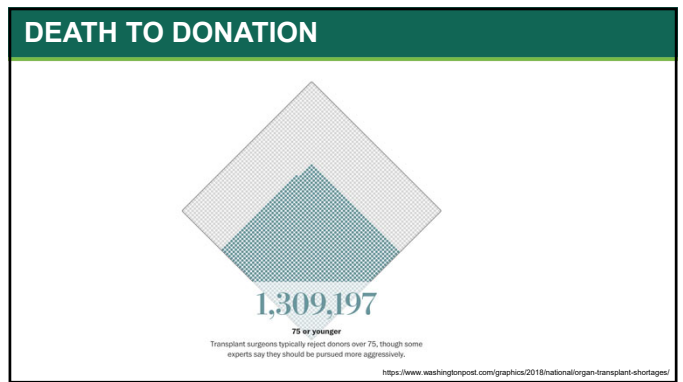
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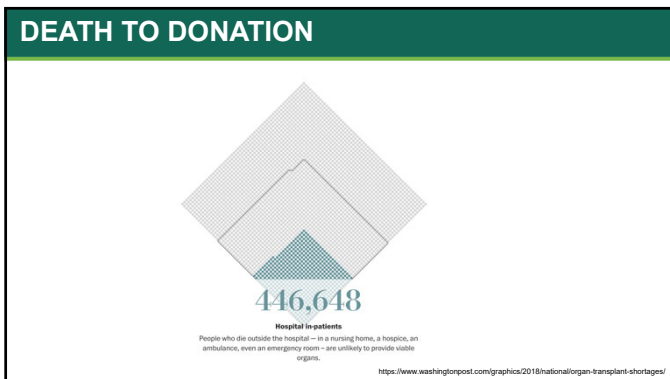
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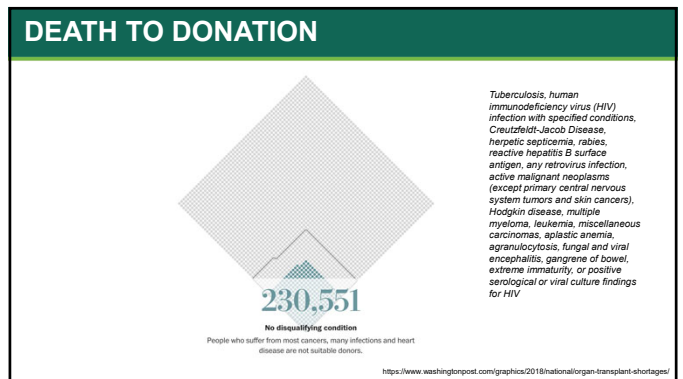
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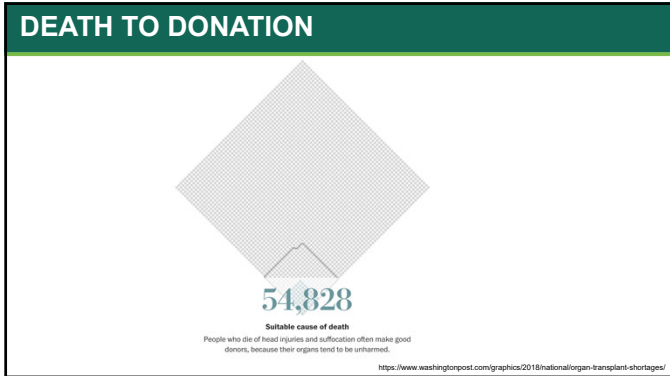
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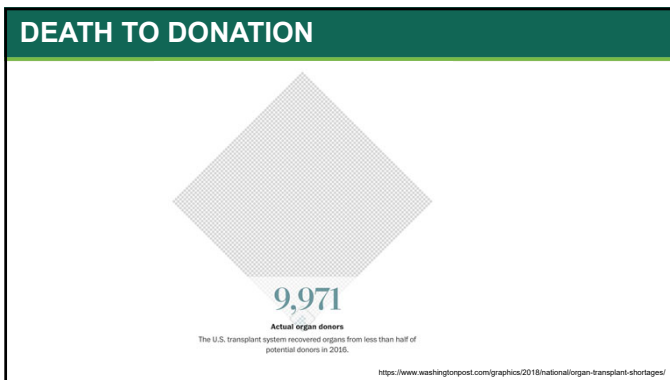
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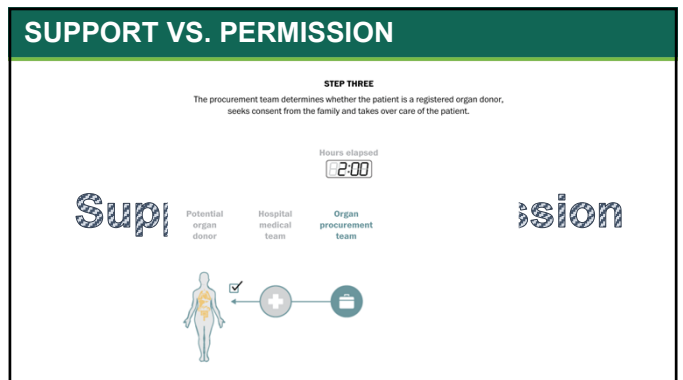
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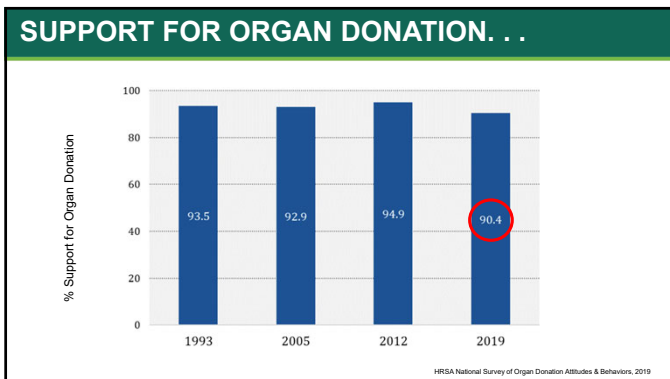
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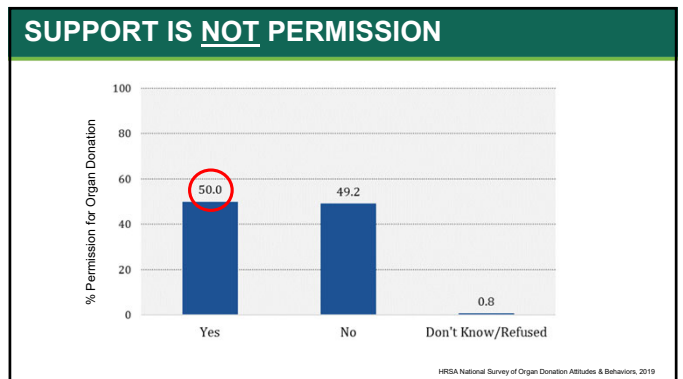
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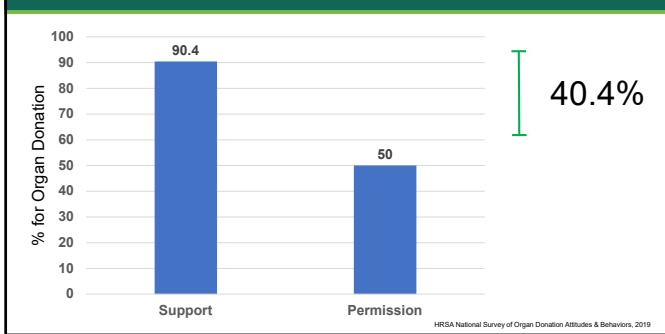


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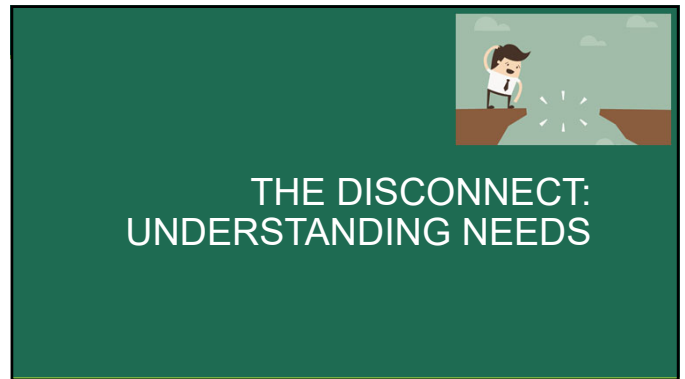


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THE DISCONNECT – SUPPORT VS. PERMISSION

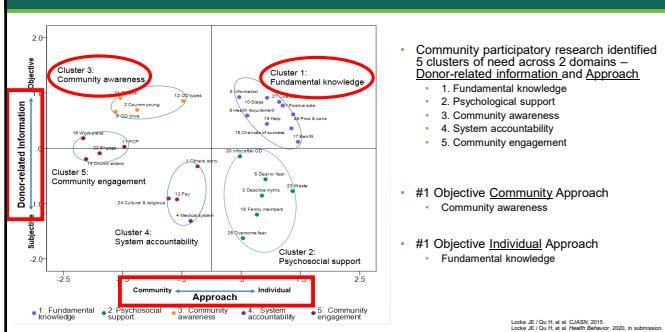


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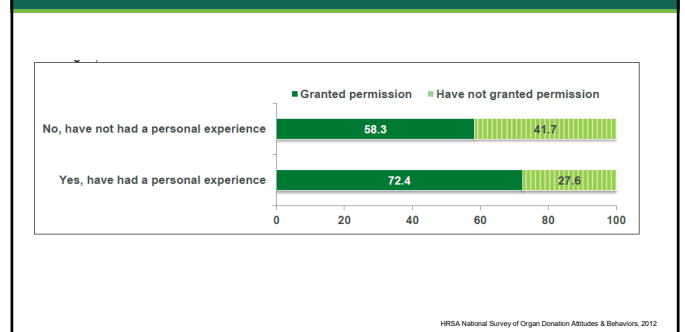
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UNDERSTANDING THE “WHY NOT?”



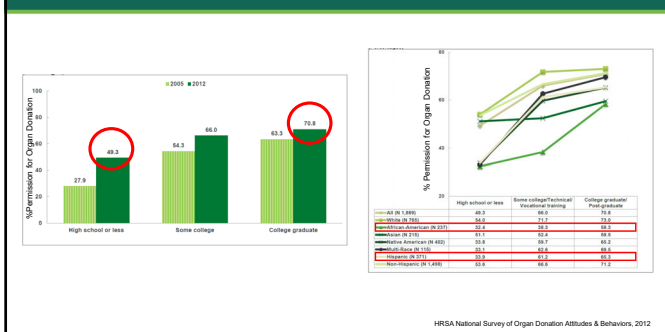
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COMMUNITY AWARENESS

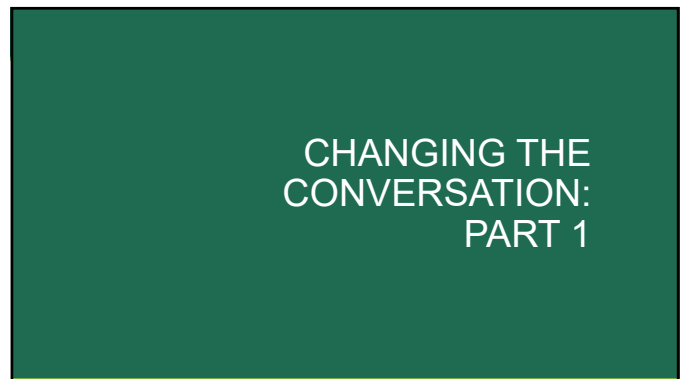


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FUNDAMENTAL KNOWLEDGE



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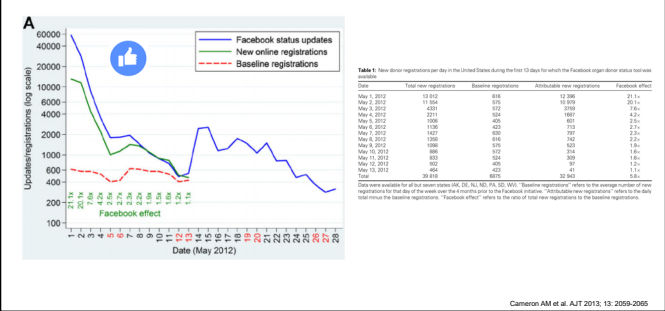
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COMMUNITY AWARENESS

1 in 8 women will get breast cancer.

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MAKING THE CONNECTION – SOCIAL MEDIA?



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MEDICAL SOCIETIES?

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REMEMBER NEED TO RELATE

1 in 8 women will get breast cancer.

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TELLING THE STORY – DO WE CONNECT?

Factor	Billboard	Donor application
Audience	Unlimited and untargeted (whoever drives by)	Patient: preselected friends and family, "Donor Champion"; extended friendship circles and strangers ("smart targeting" of those most likely to respond)
Virality	Nonviral: exposure turnover depends on location; some possible further spread by recipients of the message	Virality occurs as readers of the post share the message and use the Donor Champion mode
Nature of communication	Irregular and unconventional for most people, especially patients	Facebook is a common form of communication for millions of people worldwide, including patients
Cost	Expensive ¹	Free
Patient narrative	Unrigid	Guided
Supplementary information	Name	Donation and transplant information included, as well as a section on frequently asked questions
Ease of declining patient request	Easy; ignore billboard; no emotional attachment to stranger	Easy to ignore if Facebook post because no reply is typically expected unless positive
Ethics and regulatory affairs	Minimal; billboard vendors prohibit advertisements that violate the law	A transplant ethicist and legal team assisted with application design, including a privacy policy and terms of use

¹Monthly cost depends on size, style, and location of billboard (minimum estimate \$1000/mo).

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THE GREAT EQUALIZER

- No OPT-OUT
- No choice
- No autonomy

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AUTONOMY CAN EXIST. . . ROLE FOR ORGAN DONATION

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DEFINE YOUR LEGACY. . . CONVERSATION CHANGED

Knowledge
+ Action
= Power

Knowledge
+ Action
= Legacy
= Donation

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CHANGING THE CONVERSATION: PART 2

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KNOWLEDGE – WHERE HAVE WE GONE WRONG

No autonomy here.
How do we change the conversation?

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LEVERAGING LESSONS FROM LIVING DONATION PROGRAMS

Session	Summary of Material Covered
1	<p>Introduction to Kidney Transplantation and Live Donation</p> <ul style="list-style-type: none"> Administer baseline knowledge assessment Examine topics of renal failure, kidney transplantation, and living donation (including donor risks, benefits, eligibility, costs, and compatibility) Discuss common myths about living donation
2	<p>Initiating a Conversation with Potential Live Donor Candidates</p> <ul style="list-style-type: none"> Discuss common concerns associated with asking about donation Discuss effective communication strategies Engage in conversation examples and role-playing Reiterate importance of avoiding coercion
3	<p>Identifying a Social Network</p> <ul style="list-style-type: none"> Brainstorm social networks Share examples of success stories Assist participants with writing their story Assist participants with creating a Facebook page or writing a letter
4	<p>Living Donor and Recipient Panel/Surgeon and Nephrologist Panel/Recap</p> <ul style="list-style-type: none"> Panel of prior donors and recipients to share their story Potential donors encouraged to attend Q&A with a transplant surgeon and nephrologist Administer post-class knowledge assessment and program evaluation

Making House Calls Increases Living Donor Inquiries and Enrollments for Biopsy on the Kidney Transplant Waiting List

Live Donor Champion: Finding Live Kidney Donors by Separating the Advocates from the Patients

Enhanced Advocacy and Health Systems Training Through Patient Navigation Increases Access to Living-Donor Kidney Transplantation

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LIVING DONOR NAVIGATOR PROGRAM. . . CLOSING THE GAP

= Support

= Permission

9-fold increase in likelihood of donor screening
(aHR 9.27; 95% CI: 5.97-14.41)

7-fold increase in likelihood of donor approval
(aHR 7.74; 95% CI: 3.54-16.93)

Loeke JE et al. Transplantation 2020

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INDIVIDUAL AND COMMUNITY APPROACHES NEEDED

	Adjusted Hazard Ratio (95% CI)	p-value
LDN Self-Advocates vs. LDN Patients with Advocate	0.73 (0.37 – 1.44)	0.37
LDN Self-Advocates vs. Standard of Care	2.48 (1.26 – 4.90)	0.009
LDN Patients with Advocate vs. Standard of Care	3.39 (2.20 – 5.24)	<0.0001

- Educational programming is critical – FUNDAMENTAL KNOWLEDGE
- Enhanced by going beyond the individual – COMMUNITY AWARENESS

Kate / Locke Clin Trans 2020, in submission.

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MUST BE TARGETED TO SPECIFIC COMMUNITIES

Probability of Self-Advocacy Increases with Higher Social Vulnerability

Predicted Probability of Self-Advocacy

Overall SVI Percentile

Model adjusted for recipient Age and gender

Cumberland County, Kentucky

Albany County, New York

Carter & Kate / Locke CJASN 2020, in submission. <https://svi.usc.gov/separated-county-maps.html>

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SUSTAINABILITY...

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ENSURING TRANSPARENCY & EQUITY

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TRANSPLANT RATE

- Metric by which disparities have been defined / quantified
- OPTN defines transplant rate as the number of transplants performed per 100 years of waiting time
 - ~ transplant rate at a given center is the total number of transplants performed in a given time period divided by the waitlist size
- What's the critical assumption? . . .
 - Waitlist size accurately reflects end-stage disease burden
 - In other words, the vulnerable populations that need transplant most actually make it to the list

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ACCURATE MEASURE OF END-STAGE DISEASE IS CRITICAL

- Five of the ten states with highest ESRD prevalence were located in the Stroke Belt
- Prevalence of ESRD was positively correlated with history of stroke (rho: 0.65147, p < 0.001)

Overlapping disease prevalence underscores the need to consider disease burden in organ supply and allocation

Understanding disease burden is essential for ensuring equitable transplant access and prevention of future comorbidity

Reel R / Locke, BS, CMOF, 2020

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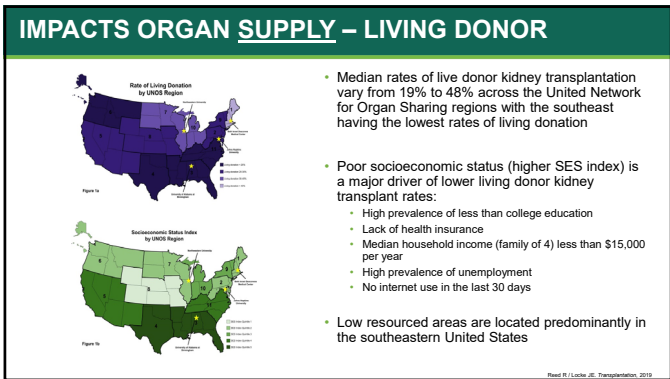
IMPACTS ORGAN SUPPLY – DECEASED DONOR

Table 3
Multivariable linear regression models for expected kidney donation rate per 100 eligible deaths

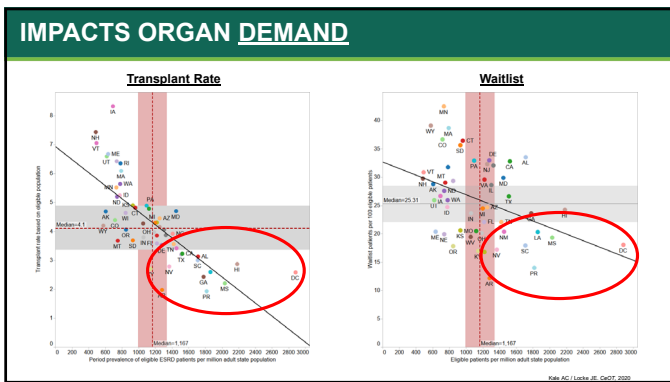
	Model I (R ² = 0.28)	Model II (R ² = 0.52)	Model III (R ² = 0.52)	Model IV (R ² = 0.37)	Model V (R ² = 0.58)										
	Est.	95% CI	P	Est.	95% CI	P	Est.	95% CI	P	Est.	95% CI	P	Est.	95% CI	P
US State DSA	-3.22	-4.62 to -1.82	0.02	0.13	-2.41 to 2.67	0.82	-2.90	-4.52 to -1.27	0.11	-0.81	-4.03 to 2.37	0.61	1.52	-1.22 to 4.26	0.27
Age															
ESRD per 100,000				-0.74	-0.99 to -0.53	<0.01				-0.89	-1.09 to -0.69	<0.01			
Diabetes				0.04	-0.09 to 0.17	0.36				2.89	-3.81 to 0.23	0.41			
Heavy alcohol use				-1.18	-3.39 to 1.08	0.30									
Poor health				-1.25	-4.68 to 1.98	0.42									
Obesity				2.20	0.29 to 4.34	0.03							-0.77	-4.42 to 2.89	0.68
Smoking				2.23	-0.29 to 4.75	0.08									
Physical inactivity				-1.79	-4.03 to 0.46	0.11									
Socioeconomic															
FPI ratio							-0.30	-0.88 to 0.28	0.20						
Poor financial							0.22	-0.75 to 0.20	0.91						
Income inequality							-0.04	-0.55 to 0.47	0.30				0.01	-0.18 to 0.20	0.99
College education							-0.03	-0.75 to 0.11	0.88						
Unemployment							-0.48	-1.04 to 0.08	0.23				2.17	-2.81 to 0.94	0.57
Uninsured							0.69	1.28 to 0.10	0.48				0.59	-1.02 to 0.20	0.46
Rurality							0.93	0.24 to 1.62	0.009				0.79	0.12 to 1.39	0.02
Social/Environmental															
PH density							0.30	-0.39 to 0.94	0.39				0.18	-0.41 to 0.78	0.54
Injury death rate							0.18	-0.54 to 0.40	0.10				-0.07	-0.21 to 0.07	0.51
MI mortality rate							-0.04	-0.26 to 0.18	0.42						
Violent crime rate							-0.02	-0.03 to -0.009	<0.01				-0.01	-0.01 to 0.003	0.19
Verbal death							0.09	-0.30 to 0.47	0.65				0.38	0.06 to 0.71	0.02

Est. = Estimate; 95% CI = 95% Confidence Interval; P = P-value; R² = R-squared; DSA = Dialysis Service Area; ESRD = end-stage renal disease; FPI = frailty index; PH = population health.

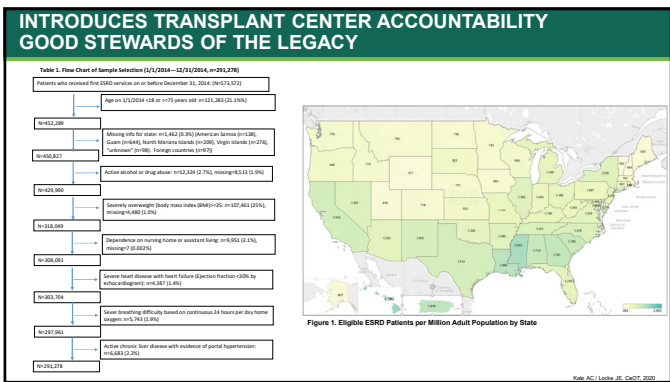
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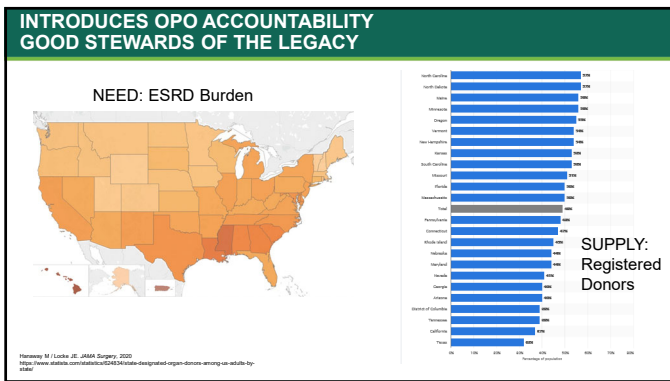
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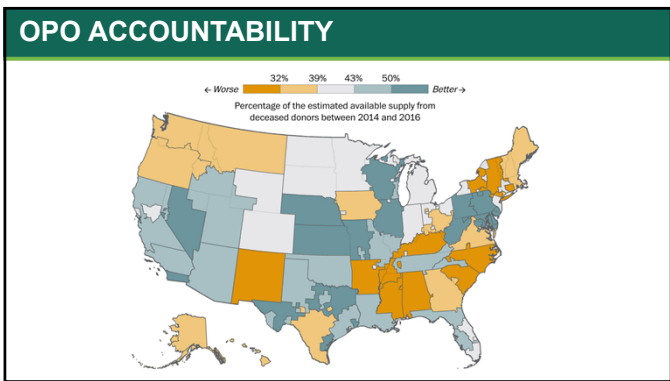
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CONTINUING THE CONVERSATION

- Metric (transplant rate) by which disparities have been defined / quantified needs to reflect actual disease burden rather than center-specific practices

HONORS THE DECISION TO DEFINE ONE'S LEGACY

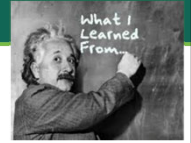
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POTENTIAL TO SUSTAIN INCREASES IN DONATION

- Centers to be held accountable for serving their population
- Allocation algorithms to ensure available organs are supplied to areas with greatest need

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TAKE HOME MESSAGE



- Organ donation can save lives
- Relate and connect to the need for organ donation
- Transparency and equity in transplantation

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DEFINE YOUR LEGACY



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THANK YOU

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