

# BARRIERS & SOLUTIONS TO INCREASING ORGAN DONATION

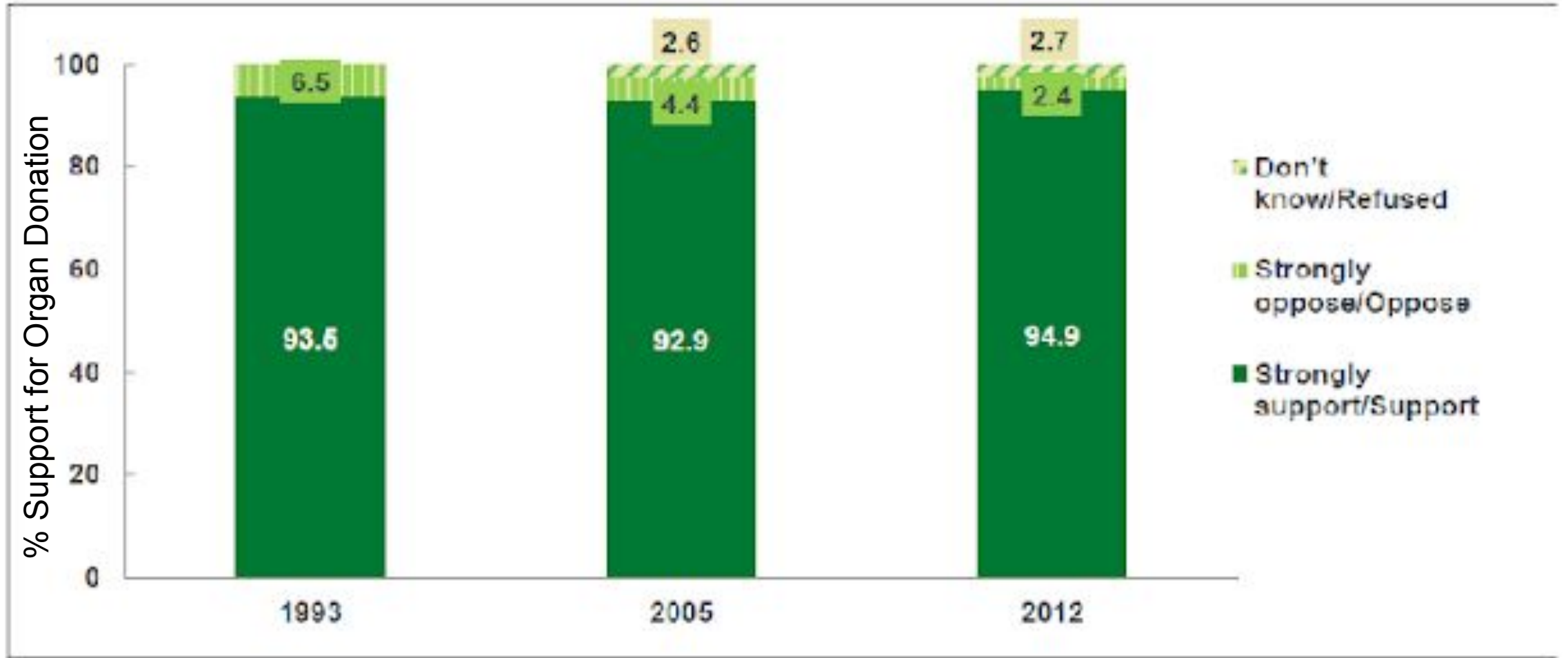
## *THE US PERSPECTIVE*

# DISCLOSURES

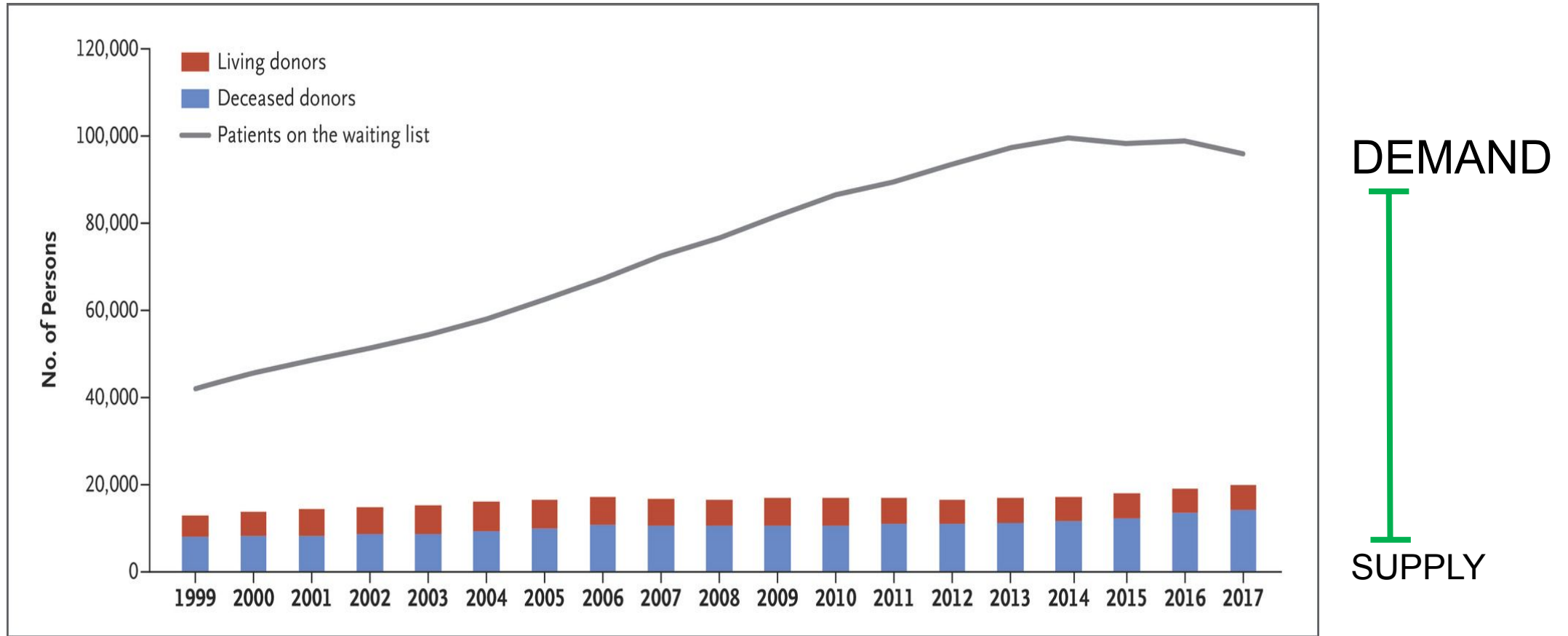
# OUTLINE

- 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*

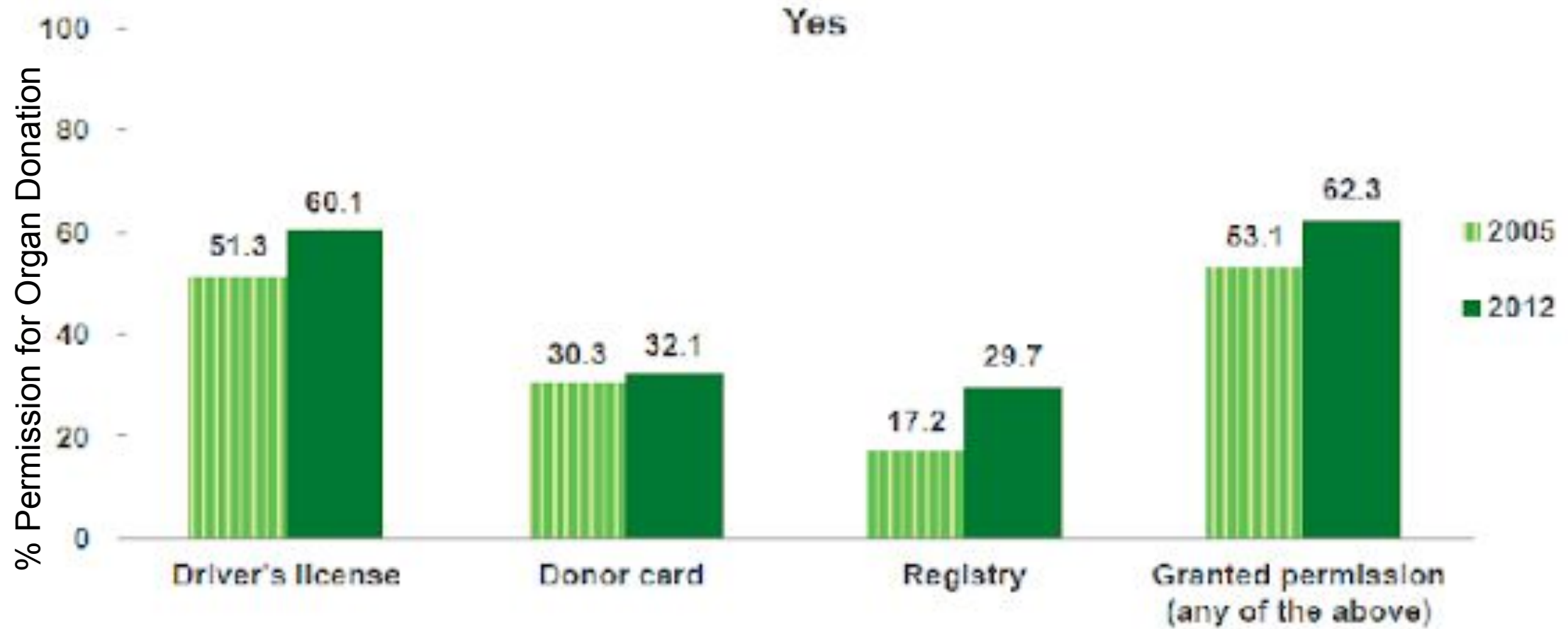
# SUPPORT FOR ORGAN DONATION...



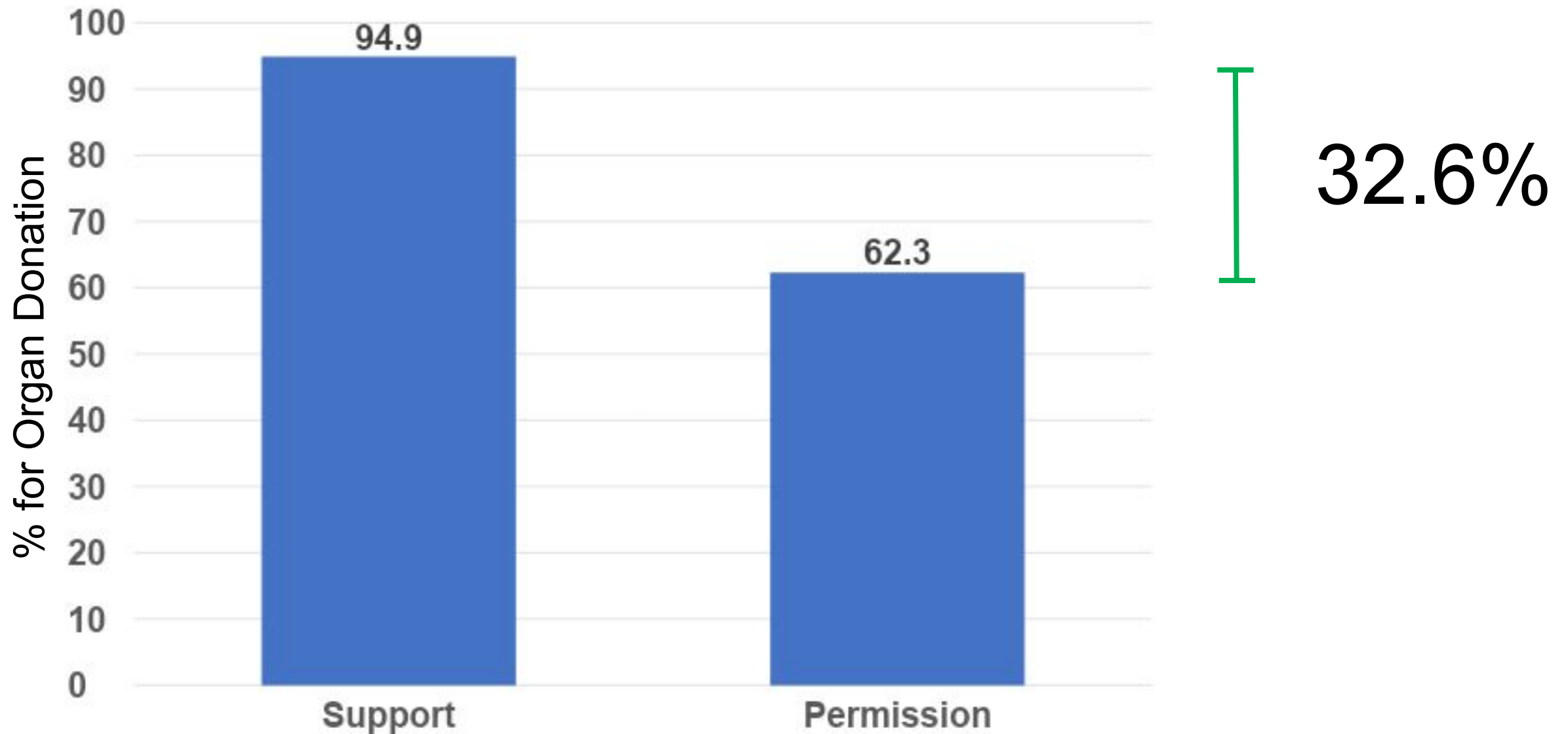
# ...YET... SUPPLY & DEMAND PROBLEM



# SUPPORT IS NOT PERMISSION



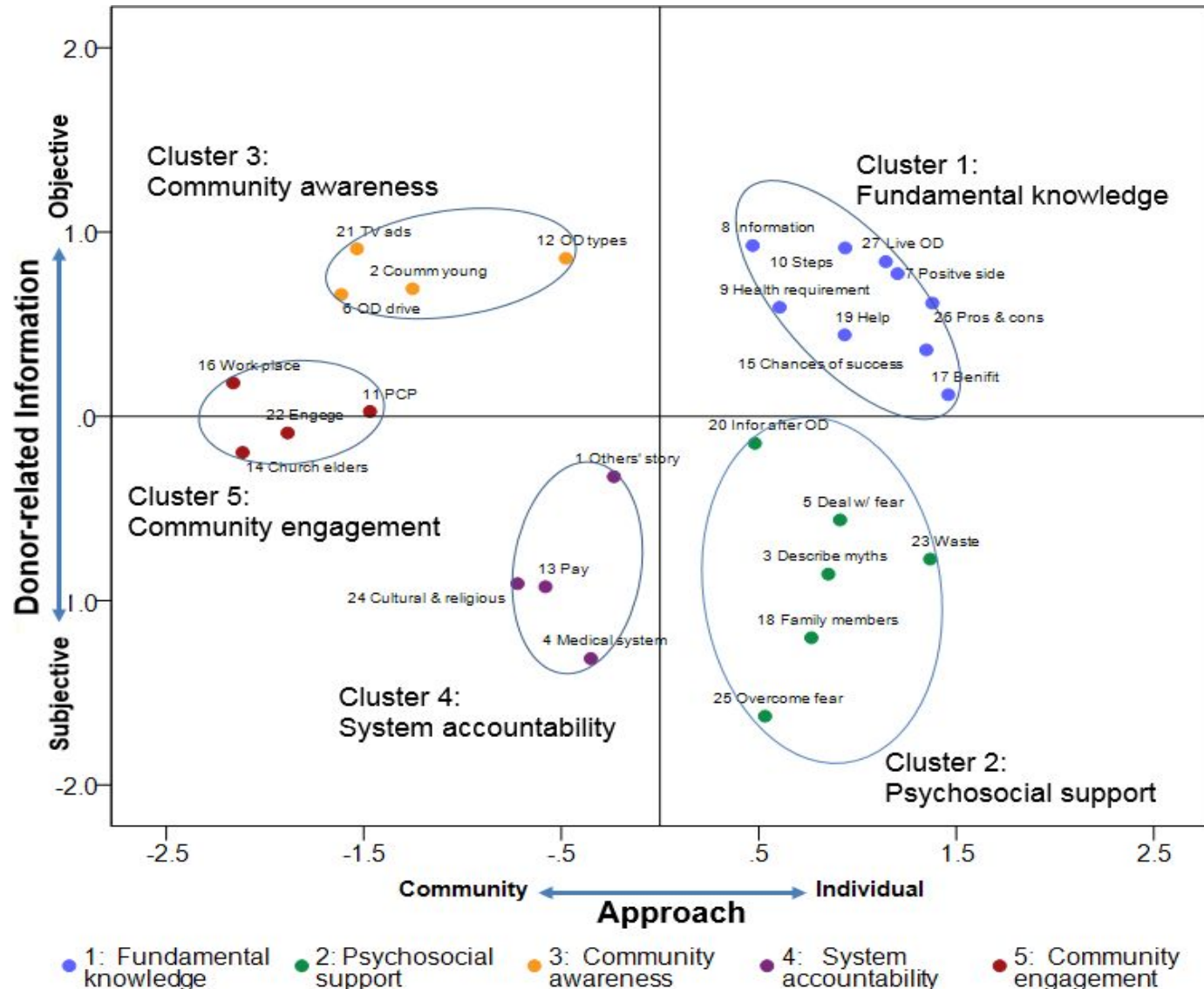
# THE DISCONNECT – SUPPORT VS. PERMISSION



# THE DISCONNECT: UNDERSTANDING NEEDS

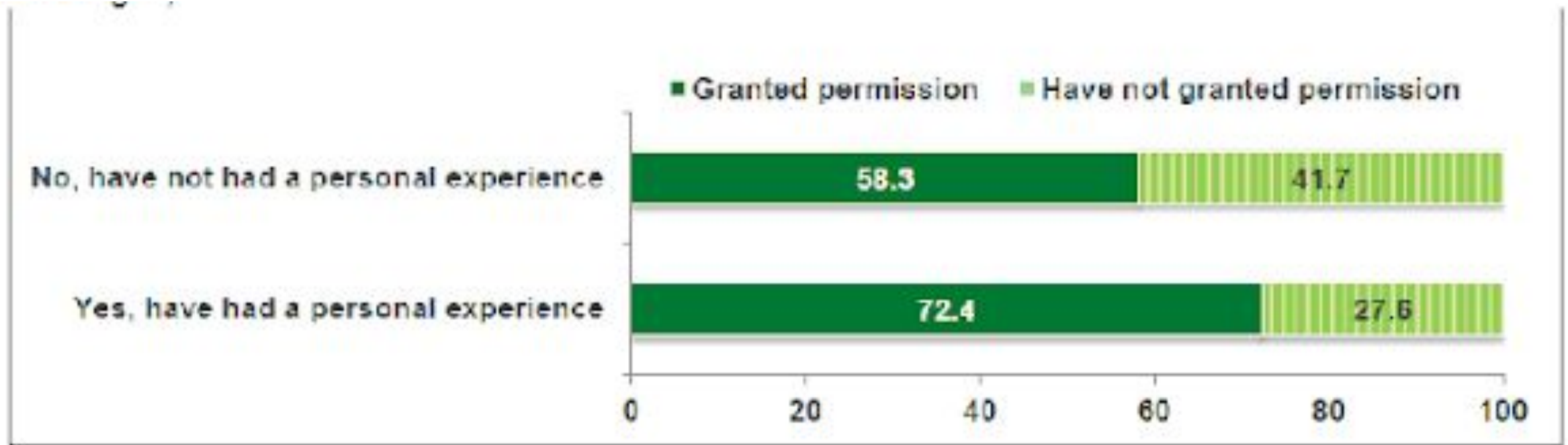


# UNDERSTANDING THE “WHY NOT?”

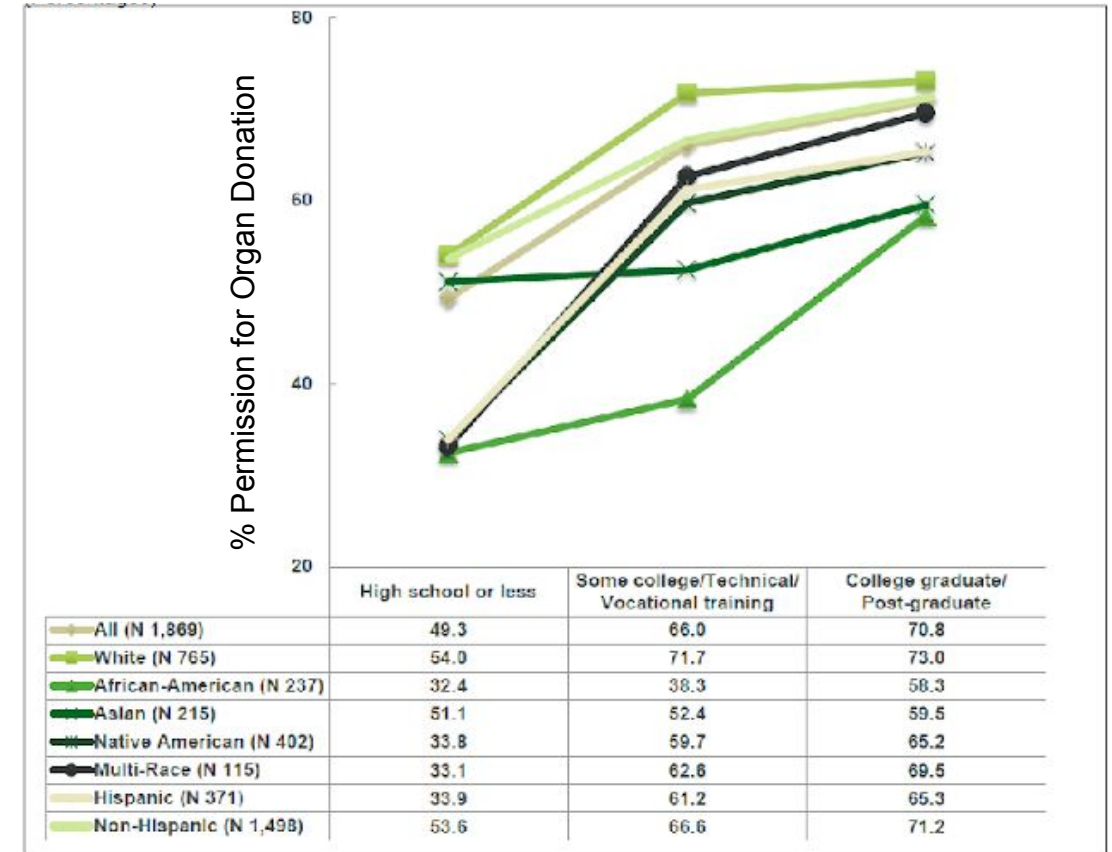
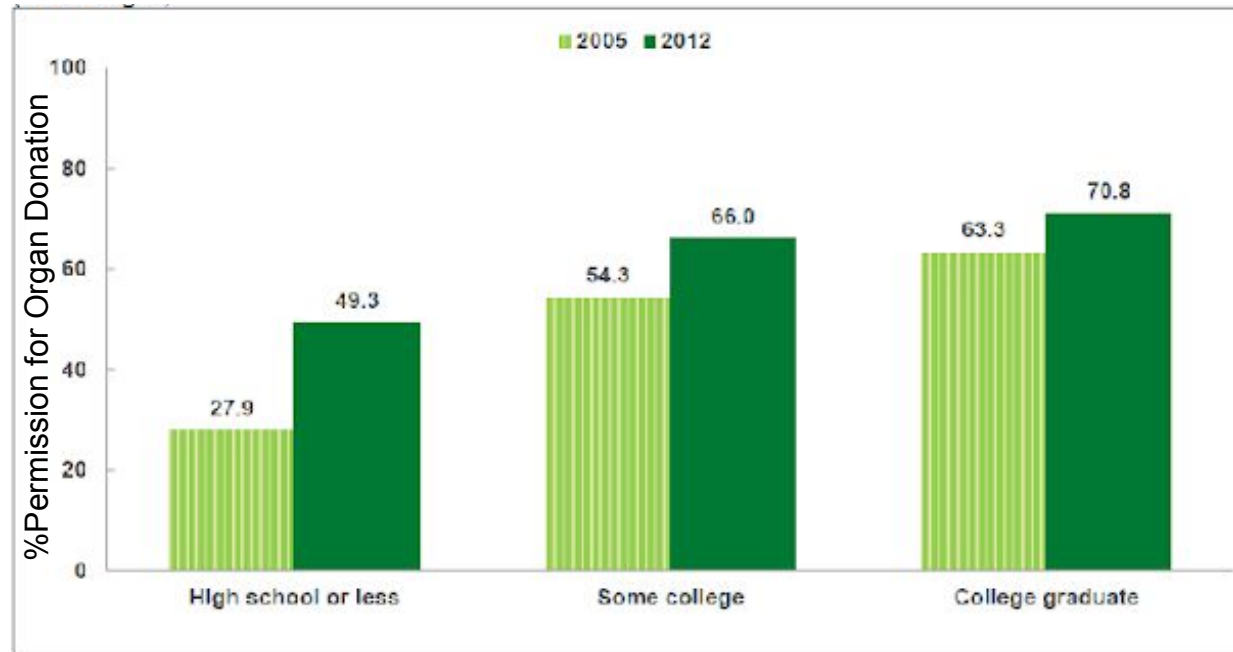


- Community participatory research identified 5 clusters of need across 2 domains – donor-related information and approach
  - 1. Fundamental knowledge
  - 2. Psychological support
  - 3. Community awareness
  - 4. System accountability
  - 5. Community engagement
- #1 Objective Community Approach
  - Community awareness
- #1 Objective Individual Approach
  - Fundamental knowledge

# COMMUNITY AWARENESS

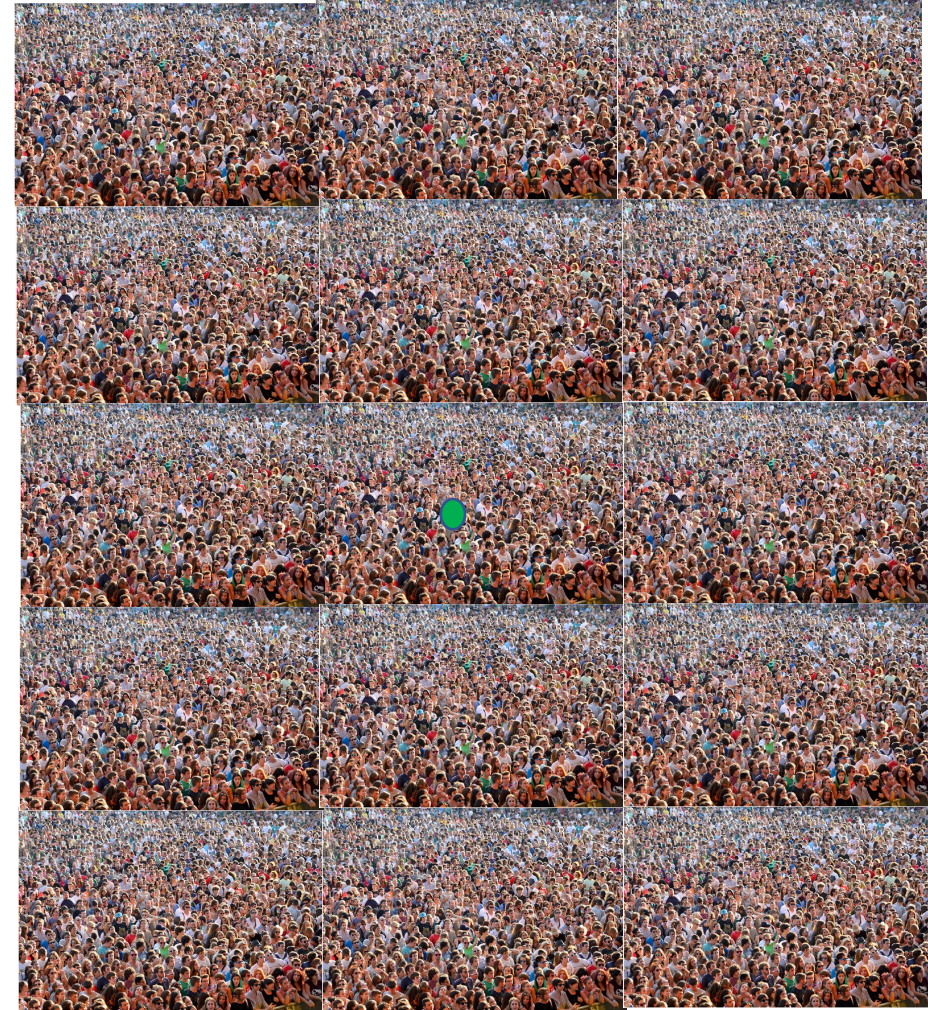


# FUNDAMENTAL KNOWLEDGE



# CHANGING THE CONVERSATION: PART 1

# COMMUNITY AWARENESS





# MAKING THE CONNECTION – SOCIAL MEDIA?

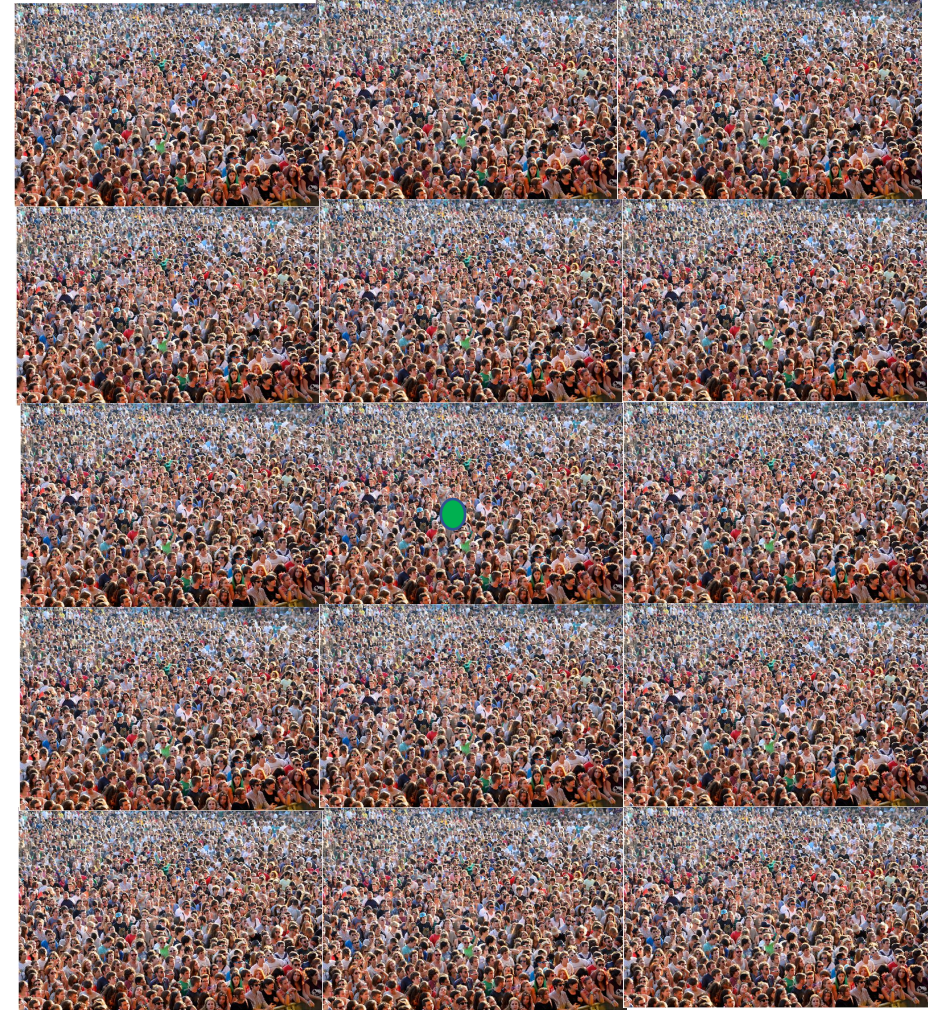


**Table 1:** New donor registrations per day in the United States during the first 13 days for which the Facebook organ donor status tool was available

Date	Total new registrations	Baseline registrations	Attributable new registrations	Facebook effect
May 1, 2012	13 012	616	12 396	21.1x
May 2, 2012	11 554	575	10 979	20.1x
May 3, 2012	4331	572	3759	7.6x
May 4, 2012	2211	524	1687	4.2x
May 5, 2012	1006	405	601	2.5x
May 6, 2012	1136	423	713	2.7x
May 7, 2012	1427	630	797	2.3x
May 8, 2012	1358	616	742	2.2x
May 9, 2012	1098	575	523	1.9x
May 10, 2012	886	572	314	1.6x
May 11, 2012	833	524	309	1.6x
May 12, 2012	502	405	97	1.2x
May 13, 2012	464	423	41	1.1x
Total	39 818	6875	32 943	5.8x

Data were available for all but seven states (AK, DE, NJ, ND, PA, SD, WV). "Baseline registrations" refers to the average number of new registrations for that day of the week over the 4 months prior to the Facebook initiative. "Attributable new registrations" refers to the daily total minus the baseline registrations. "Facebook effect" refers to the ratio of total new registrations to the baseline registrations.

# REMEMBER NEED TO RELATE

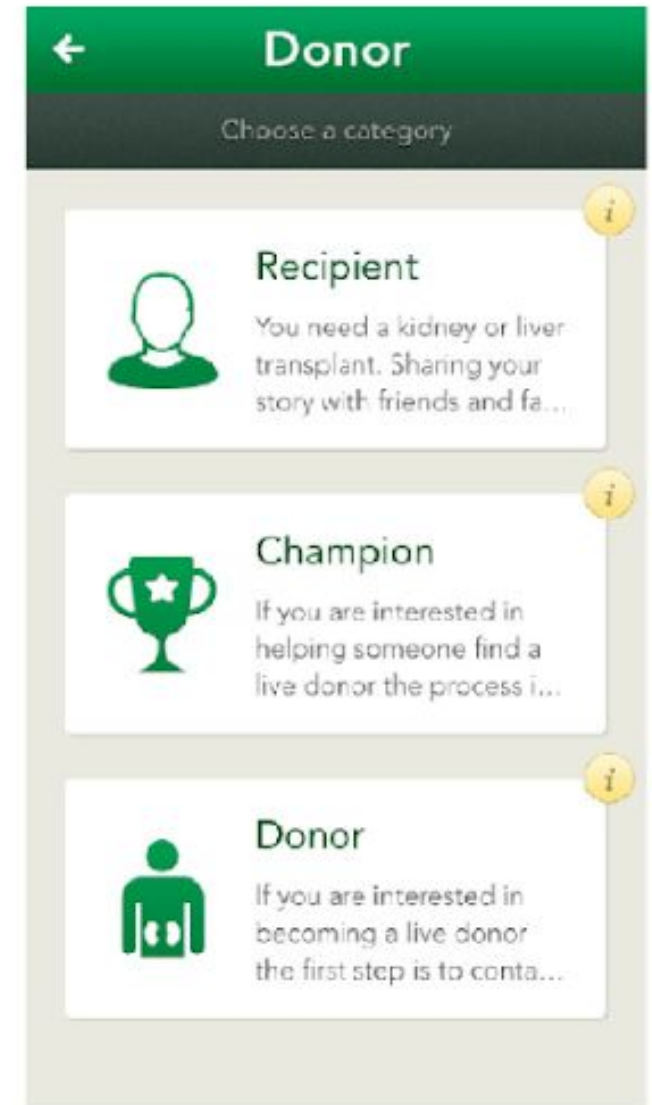


# TELLING THE STORY – DO WE CONNECT?

**Table 1:** Billboard versus the Donor Facebook-based application

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 <sup>1</sup>	Free
Patient narrative	Unguided	Guided
Supplementary information	None	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 a 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

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



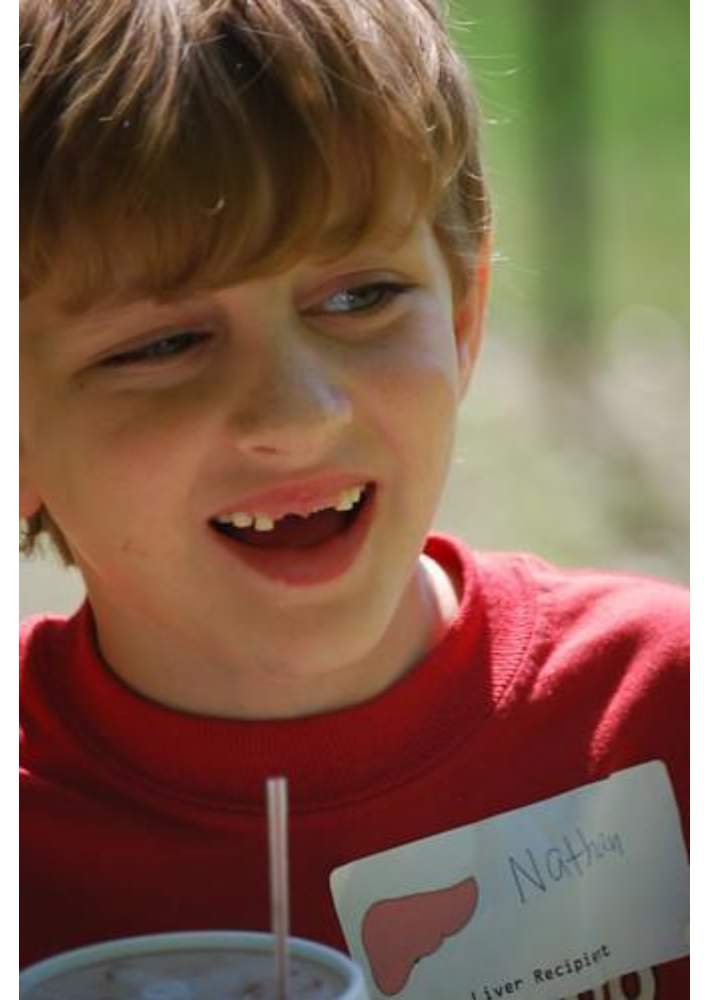


# THE GREAT EQUALIZER



- No OPT-OUT
- No choice
- No autonomy
- Anti-American

# AUTONOMY CAN EXIST. . . ROLE FOR ORGAN DONATION





# DEFINE YOUR LEGACY. . . CONVERSATION CHANGED

Knowledge  
+ Action  

---

= Power  

---

Knowledge  
+ Action  

---

= Legac  

---

= ~~Y~~ Donation

# CHANGING THE CONVERSATION: PART 2

# KNOWLEDGE – WHERE HAVE WE GONE WRONG



No autonomy here.  
How do we change the conversation?

# LEVERAGING LESSONS FROM LIVING DONATION PROGRAMS

Table 1. Summary of Material Covered in LDN Sessions

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

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

J Am Soc Nephrol  
CLINICAL AND TRANSLATIONAL RESEARCH

### Live Donor Champion: Finding Live Kidney Donors by Separating the Advocate From the Patient

Jacqueline M. Gay  
Neha A. Desai

Original Clinical Science—General



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

Jayme F. Linker, MD,<sup>1</sup> Rhiannon D. Fleet, MPH,<sup>1</sup> Wheela Kumar, MD,<sup>1</sup> Beverly Perry, MA,<sup>1</sup> Dasgrye Hendricks, MBA,<sup>1</sup> Alexis Carter, BS,<sup>1</sup> Billie A. Sirekian, MPH,<sup>1</sup> Margaux N. Musler, MD,<sup>1</sup> Paul A. MacLennan, PhD,<sup>1</sup> Huiyan Gu, PhD,<sup>1</sup> Lennie Harmon, PhD,<sup>2</sup> Clayton Yates, PhD,<sup>2</sup> and Michael J. Jurewicz, MD<sup>1</sup>

**Background.** To date, no living donation program has simultaneously addressed the needs of both transplant candidates and living donors by separating the advocacy role from the candidate and improving potential donor content with the evaluation process. We hypothesized that the development of a novel program designed to promote both advocacy and systems training among transplant candidates and their potential living kidney donors would result in sustained increases in living-donor kidney transplantation (LDKT). To this end, we developed and implemented a Living Donor Navigator (LDN) program at the University of Alabama at Birmingham (UAB). **Methods.** We included adult patients awaiting kidney-only transplantation in retrospective cohort analyses. Long live-vitalizing (LTV) procedures: kidney resection, we assessed likelihood of living donor screening and approval by participation in the LDN program. **Results.** There were 145 LDN participants and 1443 nonparticipants identified at UAB. LDN was associated with a 3-fold increased likelihood of living donor screening (adjusted hazard ratio, 3.27; 95% confidence interval, 1.67–6.41;  $P < 0.001$ ) and a 7-fold increased likelihood of having an approved living donor (adjusted hazard ratio, 7.14; 95% confidence interval, 3.64–16.53;  $P < 0.001$ ) compared with the standard of care. Analyses by participant race demonstrated higher likelihood of screened donors and a similar likelihood of having an approved donor among African Americans compared with Caucasians. **Conclusions.** These data suggest that both advocacy and systems training are needed to increase actual LDKT rates, and that LDN programs may mitigate existing racial disparities in access to LDKT.

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<sup>1</sup>University of Alabama at Birmingham, School of Medicine, Comprehensive Transplant Institute, Birmingham, AL.

<sup>2</sup>Department of Biostatistics, University of Alabama at Birmingham, Birmingham, AL.

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The authors declare no conflicts of interest.

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### INTRODUCTION

Kidney transplantation is associated with improved long-term outcomes and is considered the gold standard for treatment of end-stage renal disease (ESRD).<sup>1–3</sup> Living-donor kidney transplantation (LDKT) is associated with a significant survival benefit over deceased-donor transplantation.<sup>4–7</sup> Despite these proven benefits, LDKT has declined in the United States since 2004.<sup>8</sup> The nationwide decline appears to be multifactorial.<sup>9–11</sup> A recent survey by the National Kidney Foundation found that 1 in 4 Americans would consider living kidney donation if they knew someone who needed a kidney, and a survey from the Mayo Clinic demonstrated that 34% of individuals surveyed would donate to a friend or family member and 49% to a complete stranger.<sup>10</sup> When an article, these results would suggest that many potential donors do not know they are needed, which presents particularly problematic given that lack of knowledge about how to ask someone to donate was the most prevalent barrier to achieving LDKT identified by transplant candidates.<sup>11</sup>

Various programs have been designed to separate this advocacy role from the transplant candidate, including the Johns Hopkins Live Donor Champion Program and Smartphone app,<sup>12</sup> the House-based House Calls



# 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)

# INDIVIDUAL AND COMMUNITY APPROACHES NEEDED

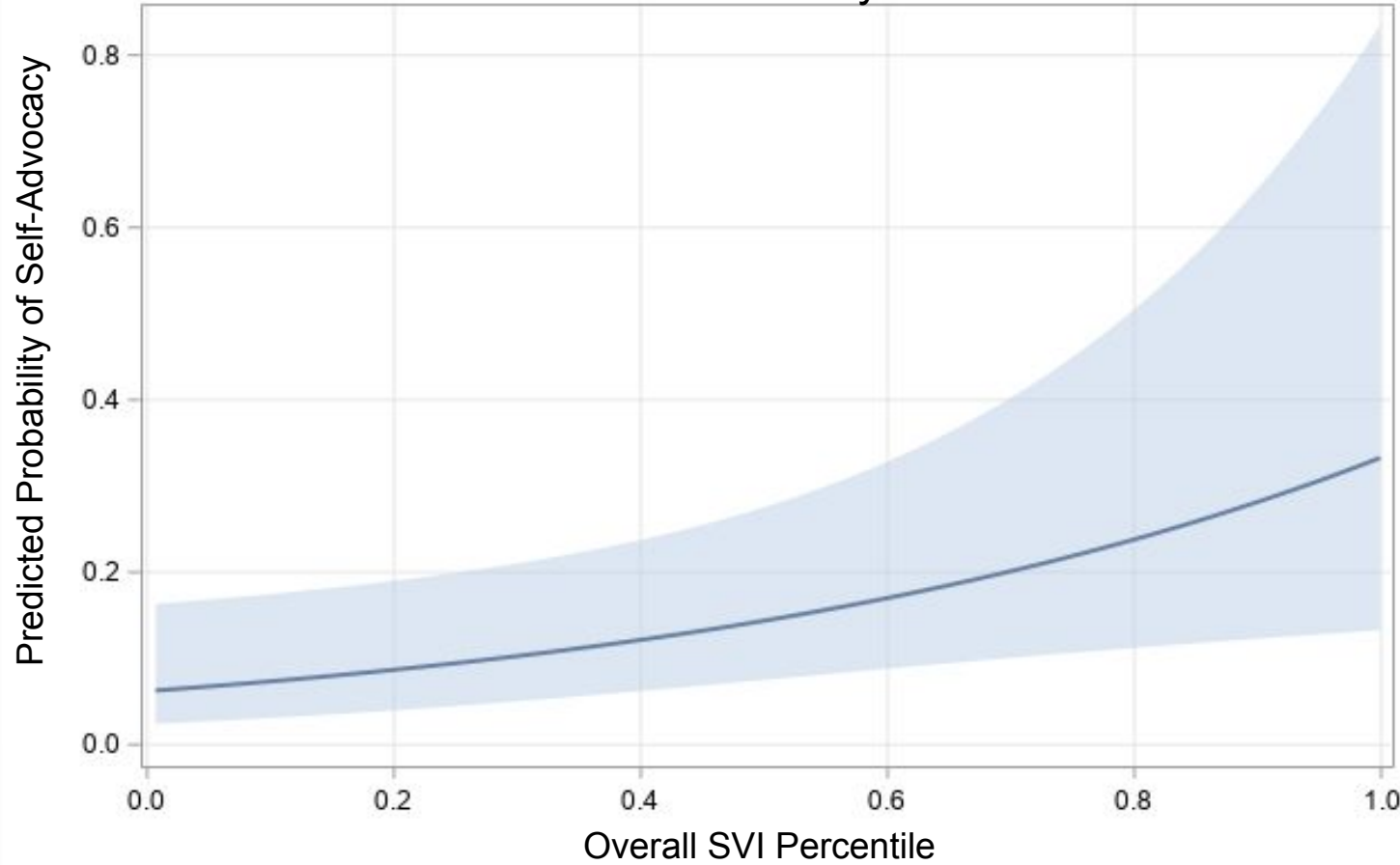
	Adjusted Hazard Ratio (95% CI)	p-value
LDN Self-Advocates vs. LDN Patients with Advocate	0.73 (0.37 – 1.44)	0.37
LDN Self-Advocates vs. Standard of Care	2.48 (1.26 – 4.90)	0.009
LDN Patients with Advocate vs. Standard of Care	3.39 (2.20 – 5.24)	<0.0001

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

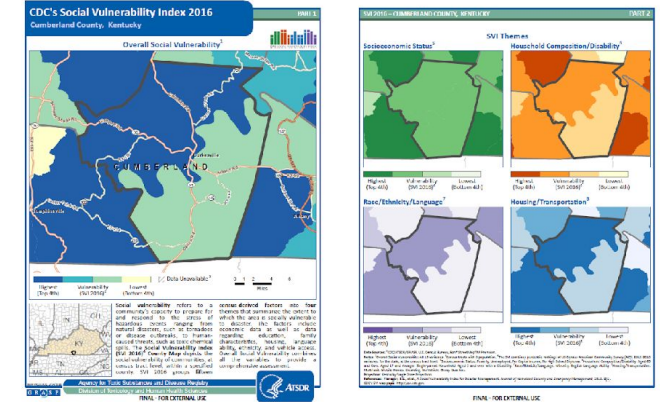


# MUST BE TARGETED TO SPECIFIC COMMUNITIES

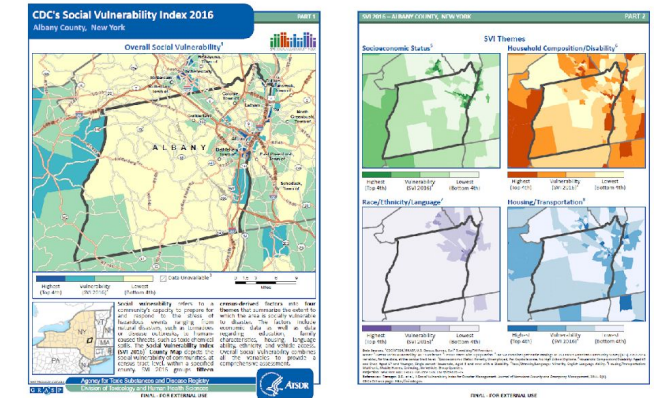
Probability of Self-Advocacy Increases with Higher Social Vulnerability



Model adjusted for recipient Age and gender



Cumberland County, Kentucky



Albany County, New York

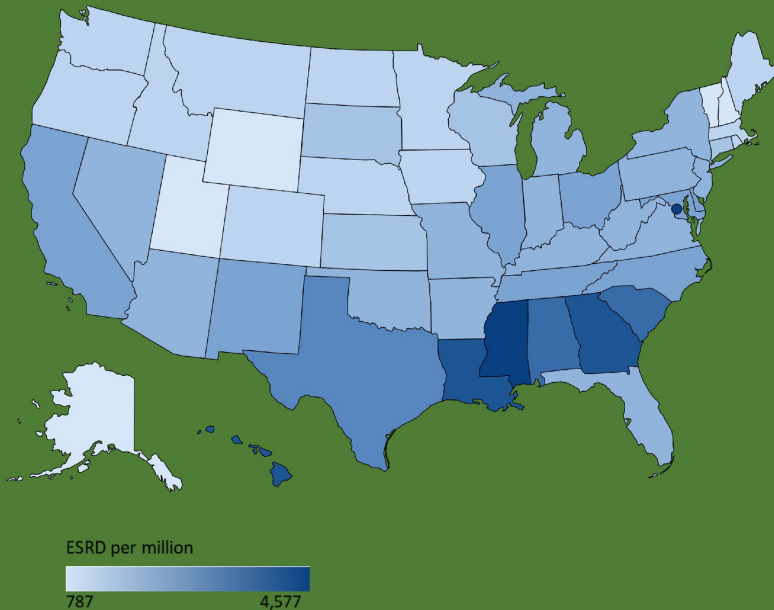
# ENSURING TRANSPARENCY & EQUITY

# 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

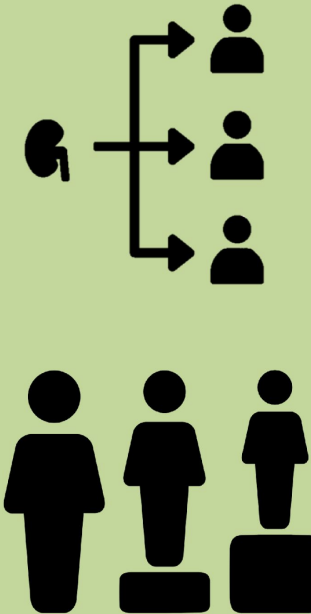
# ACCURATE MEASURE OF END-STAGE DISEASE IS CRITICAL

- 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 ( $\rho: 0.65147, p < 0.001$ )



The Stroke Belt is traditionally defined as the following states: Alabama, Arkansas, Georgia, Indiana, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Virginia.

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

# IMPACTS ORGAN SUPPLY – DECEASED DONOR

**TABLE 3.**

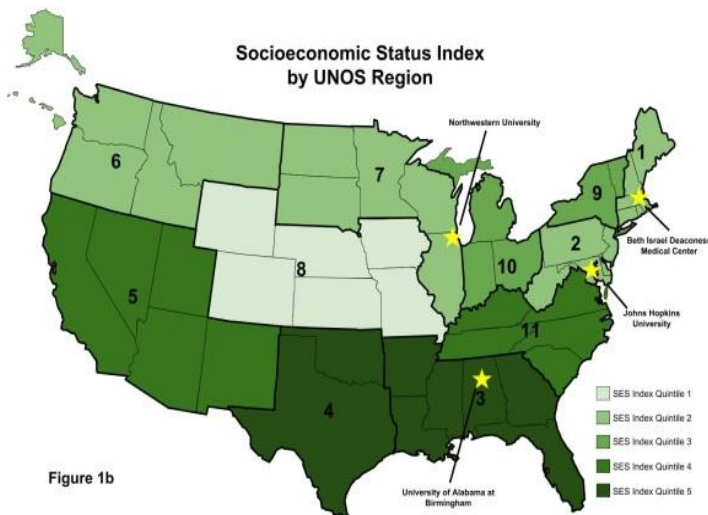
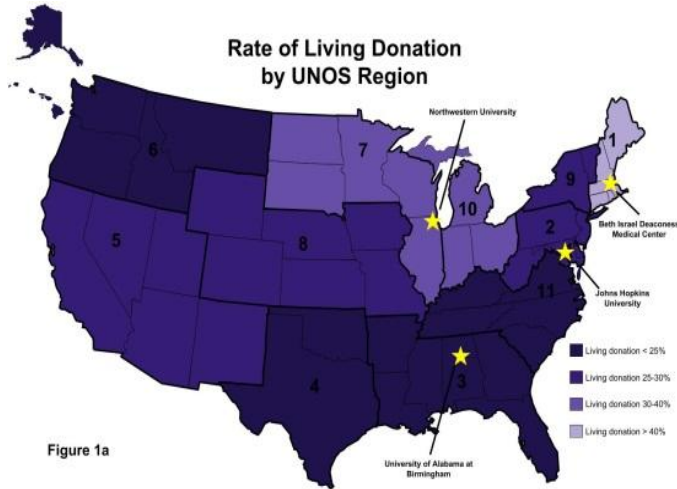
Multivariable linear regression models for expected kidney donation rate per 100 eligible deaths

	Model I (adj. R squared = 0.08)			Model II (adj. R squared = 0.85)			Model III (adj. R squared = 0.23)			Model IV (adj. R squared = 0.37)			Model V (adj. R squared = 0.58)		
	Est.	95% CI	P	Est.	95% CI	P	Est.	95% CI	P	Est.	95% CI	P	Est.	95% CI	P
Gulf State OSA Health	-3.62	-8.42 to 0.60	0.02	0.13	-2.41 to 2.67	0.92	-2.00	-6.52 to 0.72	0.11	-0.81	-4.00 to 2.37	0.61	1.52	-1.22 to 4.26	0.27
ESRD per 100 000				-0.74	-0.95 to -0.53	<0.01							-0.55	-0.90 to -0.40	<0.01
Diabetes				4.04	-3.09 to 11.17	0.25							2.59	-3.81 to 9.20	0.41
Heavy alcohol use				-1.16	-3.39 to 1.08	0.30									
Poor health				-1.30	-4.48 to 1.89	0.42							-0.77	-4.42 to 2.89	0.65
Obesity				2.29	0.23 to 4.34	0.03									
Smoking				2.22	-0.29 to 5.75	0.05									
Physical inactivity				-1.75	-4.03 to 0.45	0.11									
Socioeconomic															
PCP ratio							-0.30	-0.88 to 0.28	0.30						
Food insecurity							0.22	-3.75 to 4.21	0.91						
Income inequality							-2.24	-5.95 to 1.47	0.30				0.01	-3.13 to 3.20	0.93
College attainment							-0.23	-2.17 to 2.11	0.93						
Unemployment							-3.48	-10.54 to 3.58	0.33				2.17	-2.61 to 6.94	0.37
Uninsurance							0.39	-1.25 to 2.04	0.43				0.58	-1.02 to 2.20	0.43
Racism							0.93	0.21 to 1.62	0.009				0.75	0.12 to 1.39	0.02
Societal/Environmental															
Poll density										0.30	-0.36 to 0.94	0.39	0.16	-0.41 to 0.73	0.54
Injury death rate										0.18	-0.04 to 0.40	0.10	-0.07	-0.21 to 0.07	0.31
IV mortality rate										-0.24	-0.82 to 0.34	0.42			
Violent crime rate										-0.02	-0.05 to -0.009	<0.01	-0.01	-0.01 to 0.003	0.19
Overdose death rate										0.09	-0.32 to 0.47	0.65	0.38	0.06 to 0.71	0.02

Bold indicates significance <0.05.

CI, confidence interval; OSA, Oronston Service Area; ESRD, end-stage renal disease; PCP, primary care physician.

# IMPACTS ORGAN SUPPLY – LIVING DONOR

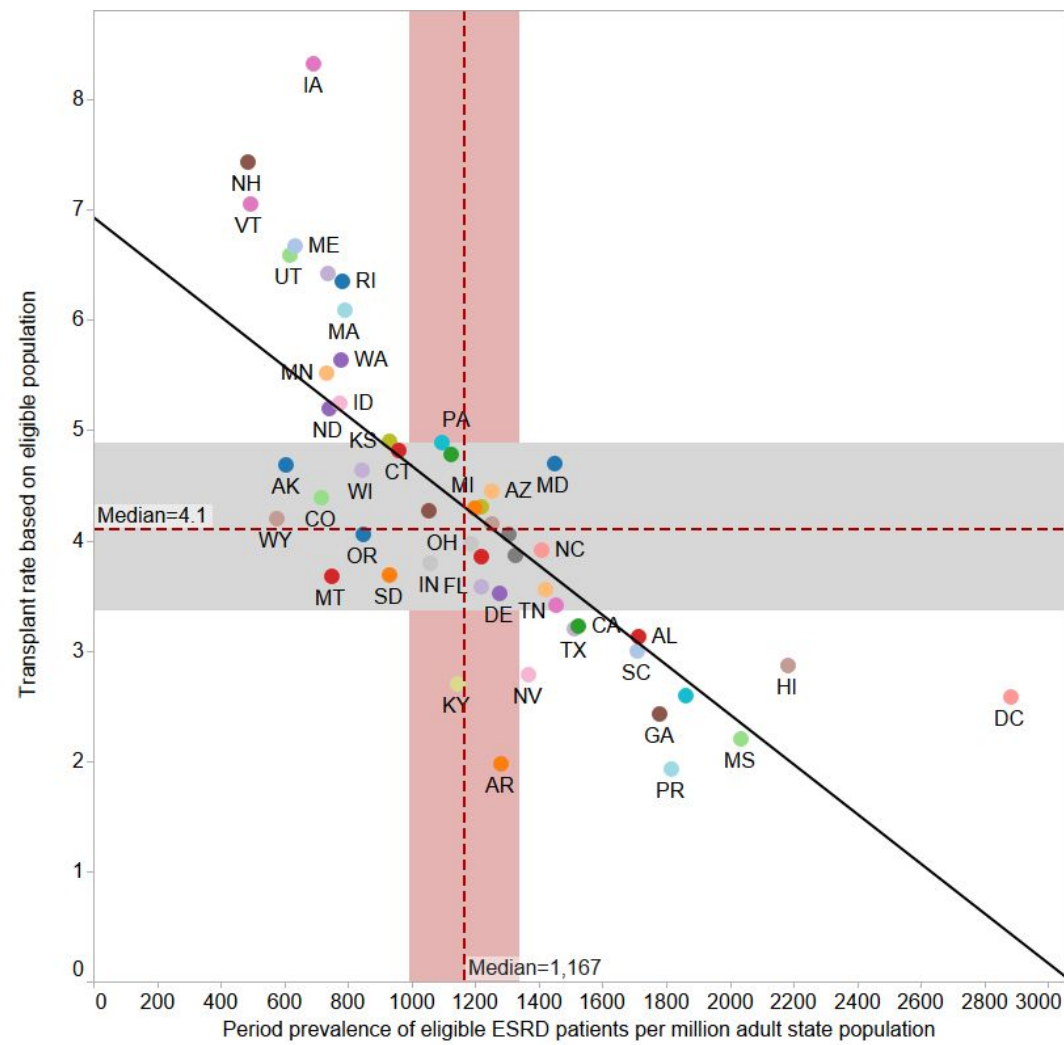


- Median rates of live donor kidney transplantation vary from 19% to 48% across the United Network for Organ Sharing regions with the southeast having the lowest rates of living donation
- Poor socioeconomic status (higher SES index) is a major driver of lower living donor kidney transplant rates:
  - High prevalence of less than college education
  - Lack of health insurance
  - Median household income (family of 4) less than \$15,000 per year
  - High prevalence of unemployment
  - No internet use in the last 30 days
- Low resourced areas are located predominantly in the southeastern United States

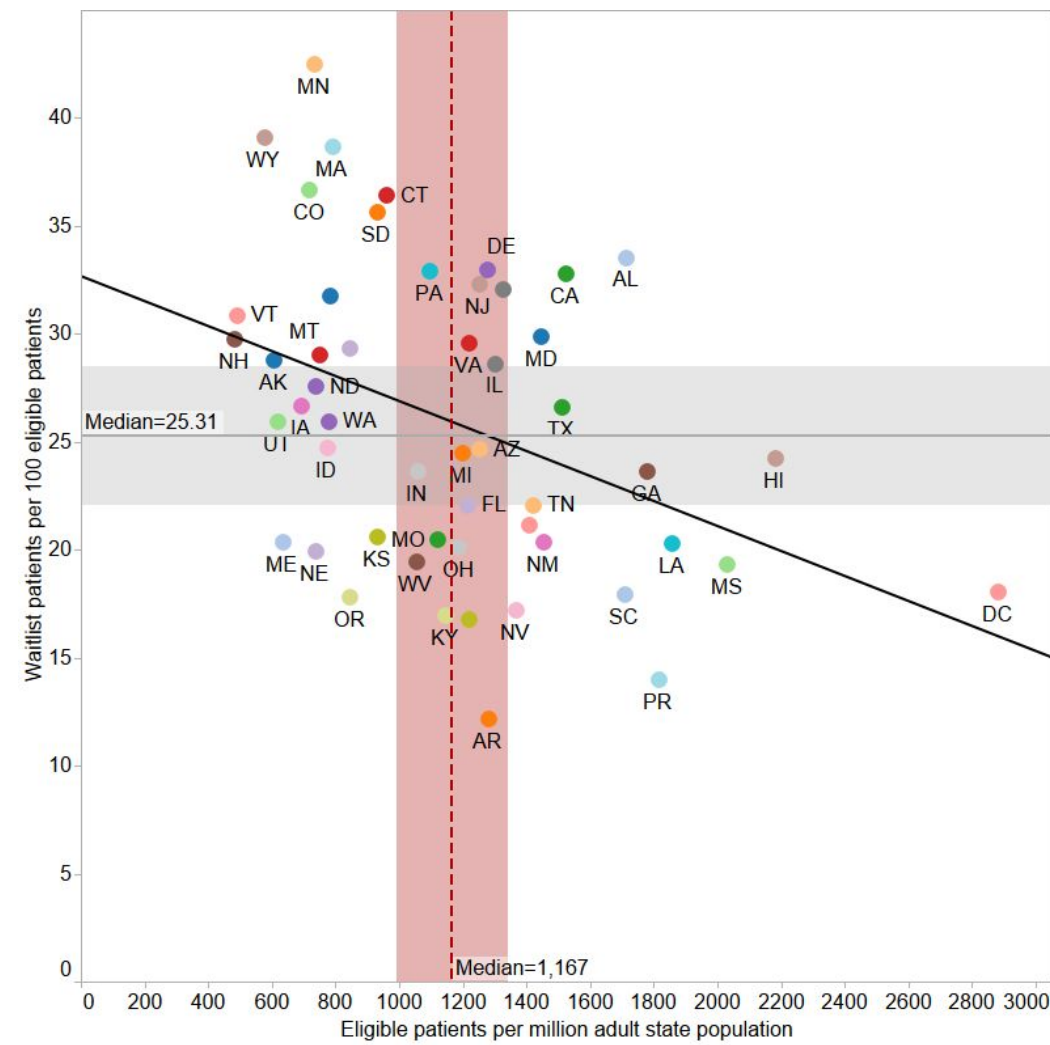


# IMPACTS ORGAN DEMAND

Transplant Rate



Waitlist



# INTRODUCES TRANSPLANT CENTER ACCOUNTABILITY

## GOOD STEWARDS OF THE LEGACY

Table 1. Flow Chart of Sample Selection (1/1/2014–12/31/2014, n=291,278)

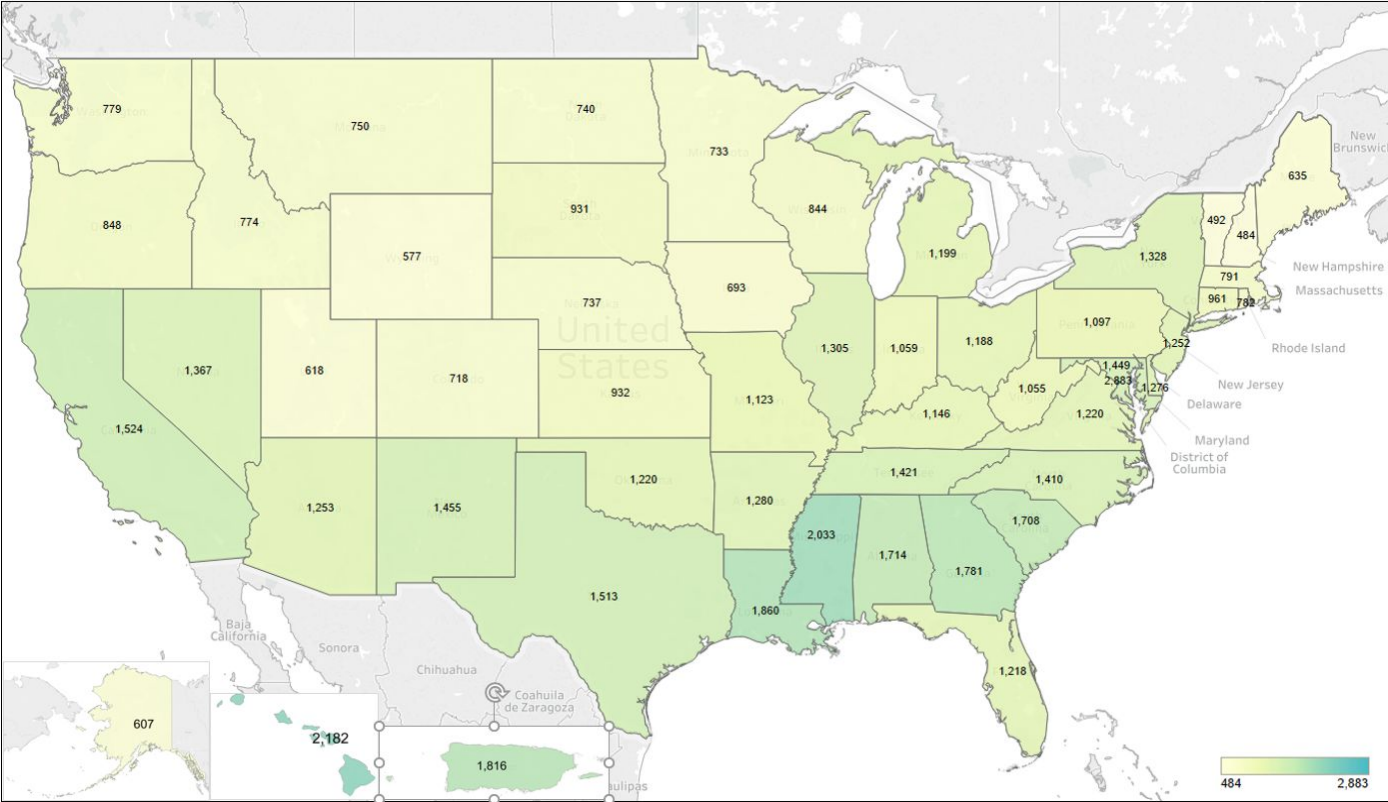
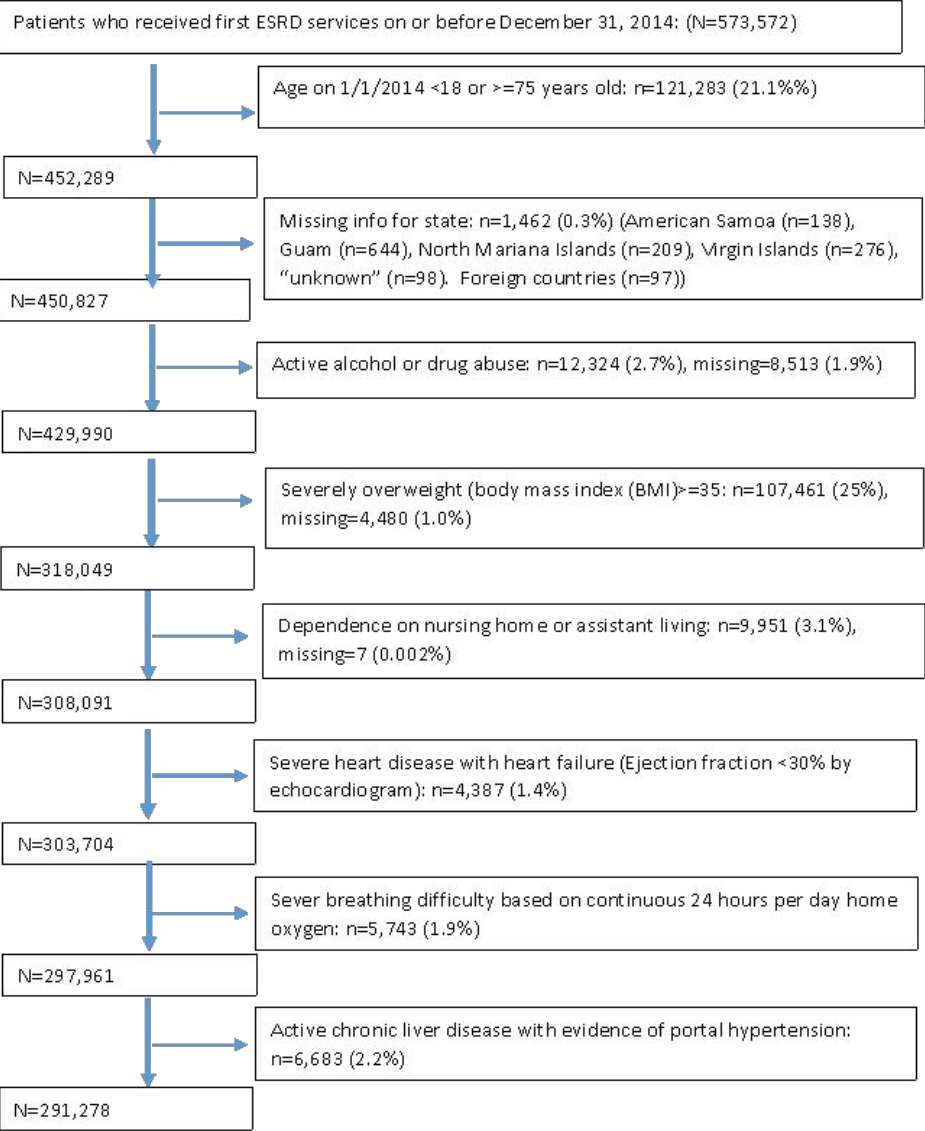


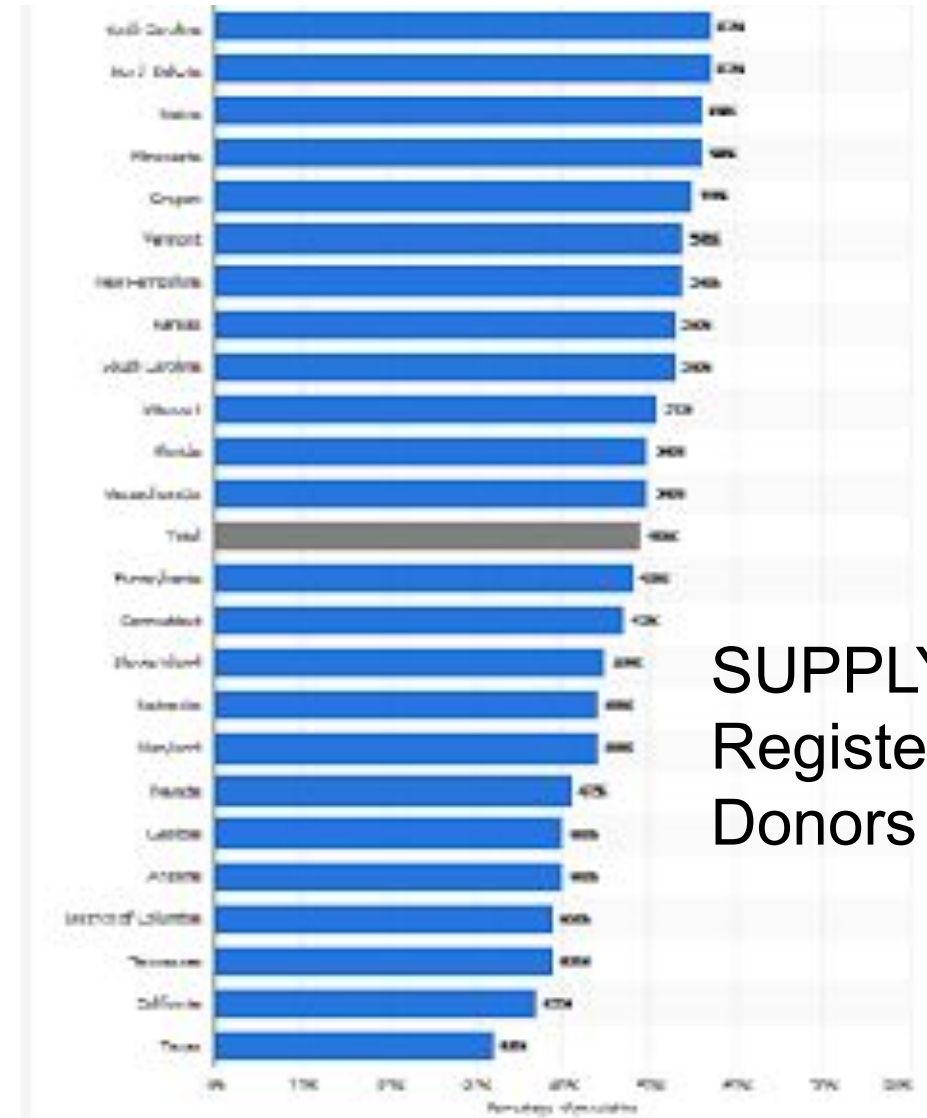
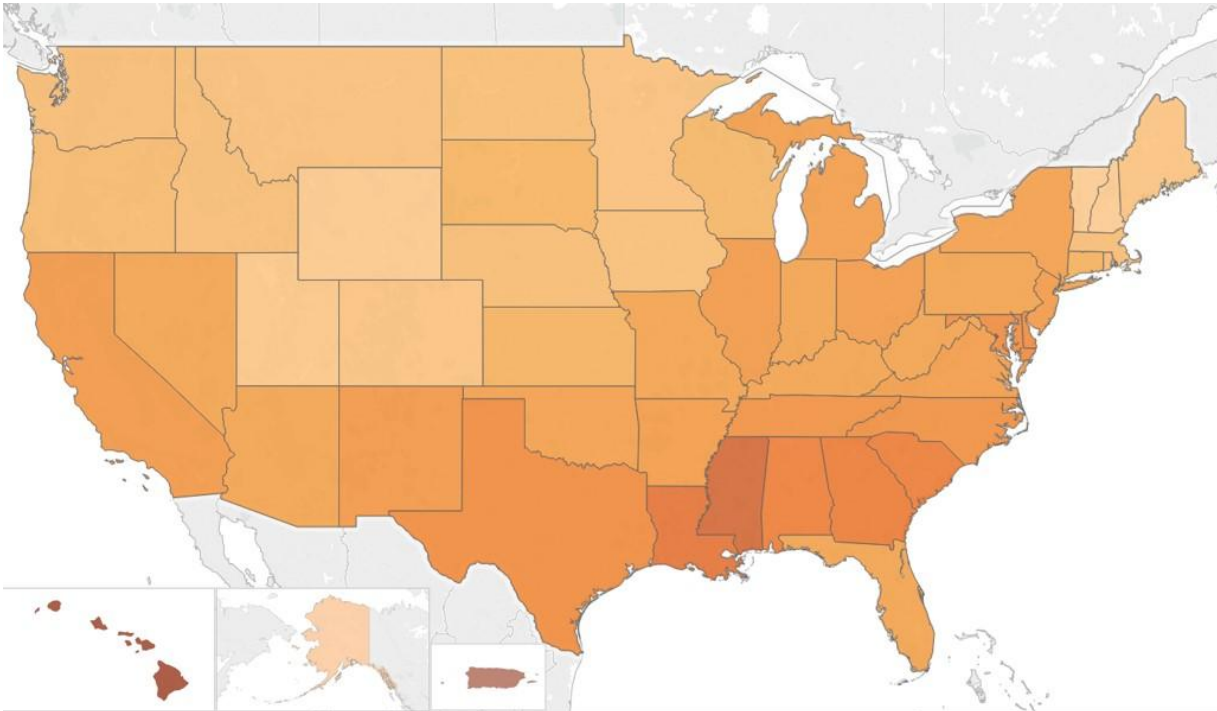
Figure 1. Eligible ESRD Patients per Million Adult Population by State



# INTRODUCES OPO ACCOUNTABILITY

## GOOD STEWARDS OF THE LEGACY

### NEED: ESRD Burden



SUPPLY:  
Registered  
Donors

# 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

=

POTENTIAL TO SUSTAIN INCREASES IN DONATION

• E

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