

Liver Transplant Access in Underserved populations: Opportunities for Targeted Interventions

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CUTTING EDGE of **TRANSPLANTATION**

TRANSPLANT SUMMIT 2019

NO SIZE FITS ALL: *Uncovering the
Potential of Personalized Transplantation*

Disclosure

NIH/ NIDDK R01

A Culturally Targeted Transplant Program to
Increase Live Donation in Hispanics
(R01DK104876)

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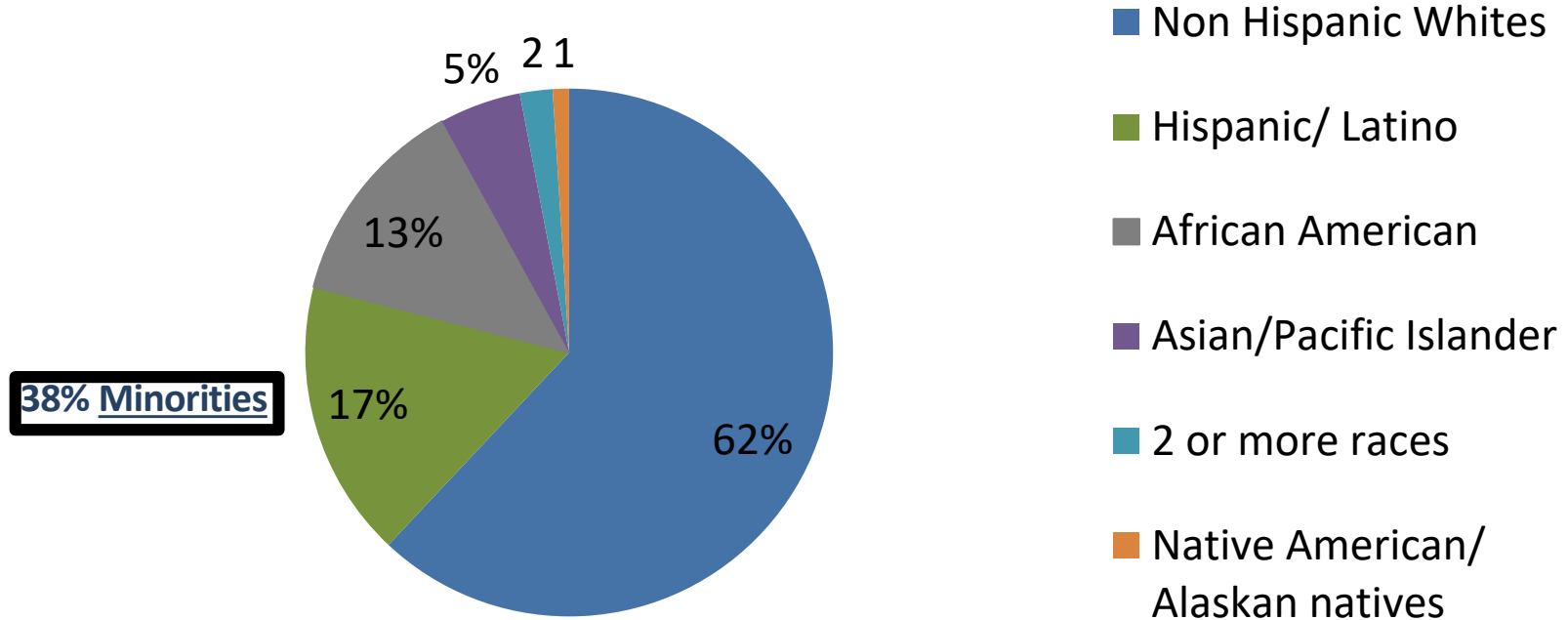
Elisa J Gordon, PhD, MPH

Learning Objectives

- 1- To understand transplant patients racial and ethnic characteristics in US
- 2- To describe how transplant programs are dealing with diverse populations in US.
Are the transplant programs personalizing their patient approach or
“one size fits all”?
- 3- To Articulate cultural and linguistic issues and Hispanic patient preferences that can inform strategies for improving transplant access, living kidney – liver donation and transplantation in Hispanics.
- 4- To Describe how a transplant based targeted initiative can improve transplant access, increase living kidney - liver donation and transplantation in Hispanics.

1- Relevant Minorities Facts

US Population

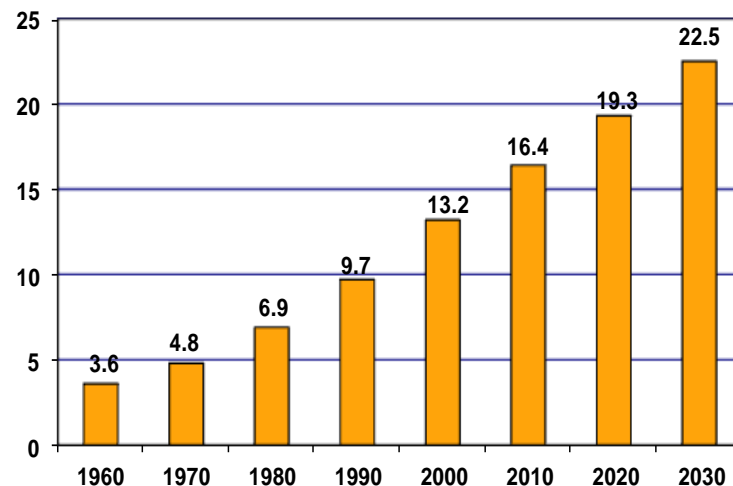


Source: US Census Bureau, 2014 National Projections

Hispanic American Facts

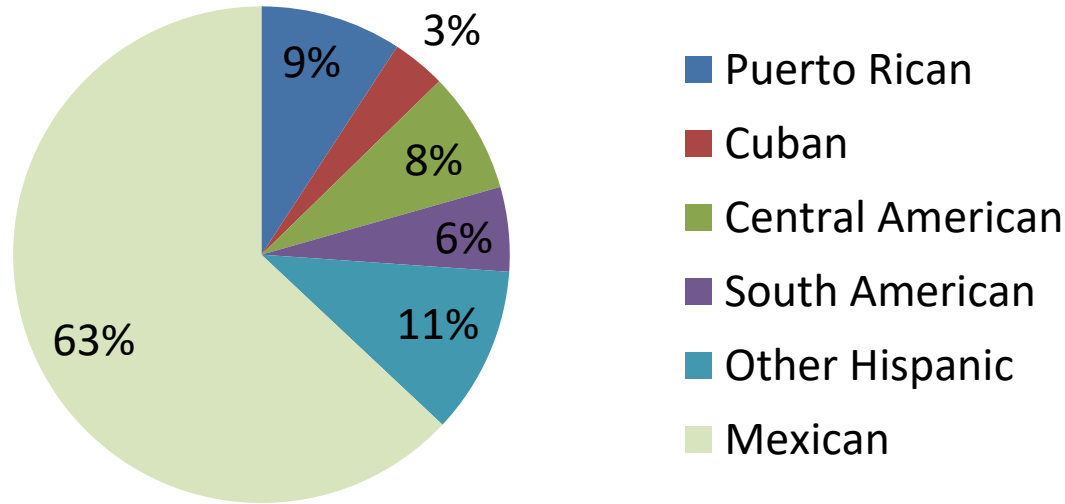
- US: 310 million population
- Hispanic Americans (HA)
50.5 million (16.3%)
“Largest minority”
- Fastest growth:
43%(HA) vs. 5% (Non- HA)
(2000-2010)
- **Hispanics accounted for more than half of the nation’s growth**
(2000-2010)
- Younger than general population: Median **28y**
2010

Percent Hispanic of U.S.
Population, 1960-2030



Source: U.S. Census Bureau

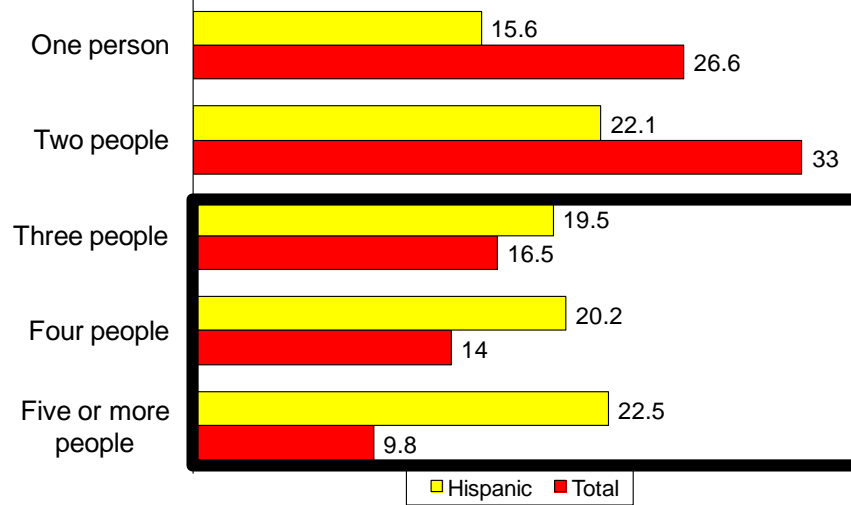
Percent Distribution of Hispanic Americans by Type in USA



US Census Bureau. 2010 data.

Households by Size and Hispanic Origin in USA

(Percent distribution of all households)



Source: Current Population Survey, Annual Social and Economic Supplement 2006

The importance of the Hispanic consumer should be a wake –up call to corporate America

- Hispanic consumers spend \$1.3 trillion in 2015
- Total buying power has increased 50% since 2010

The Hispanic market is one of the main drivers of the overall consumer markets

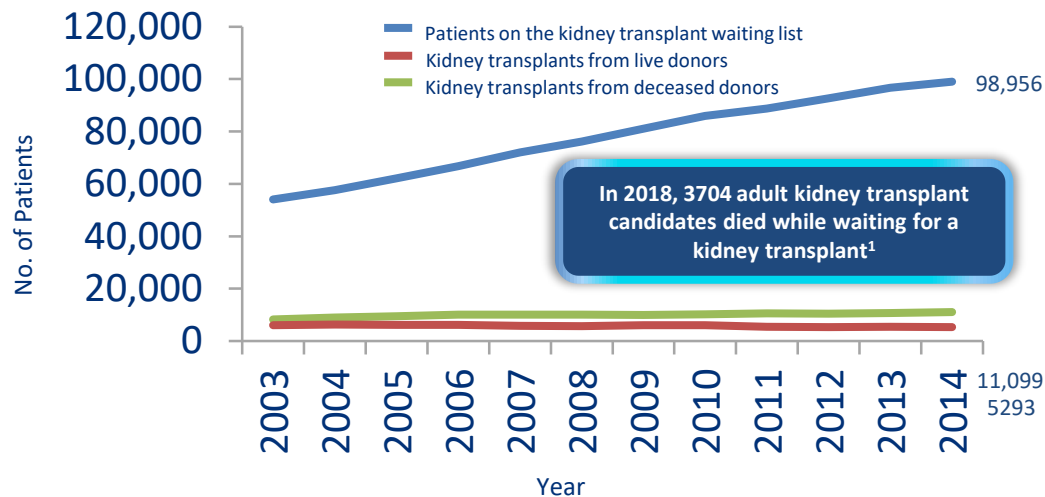


“Multicultural economic report” 2015

Terry College’s Selig Center for Economic Growth

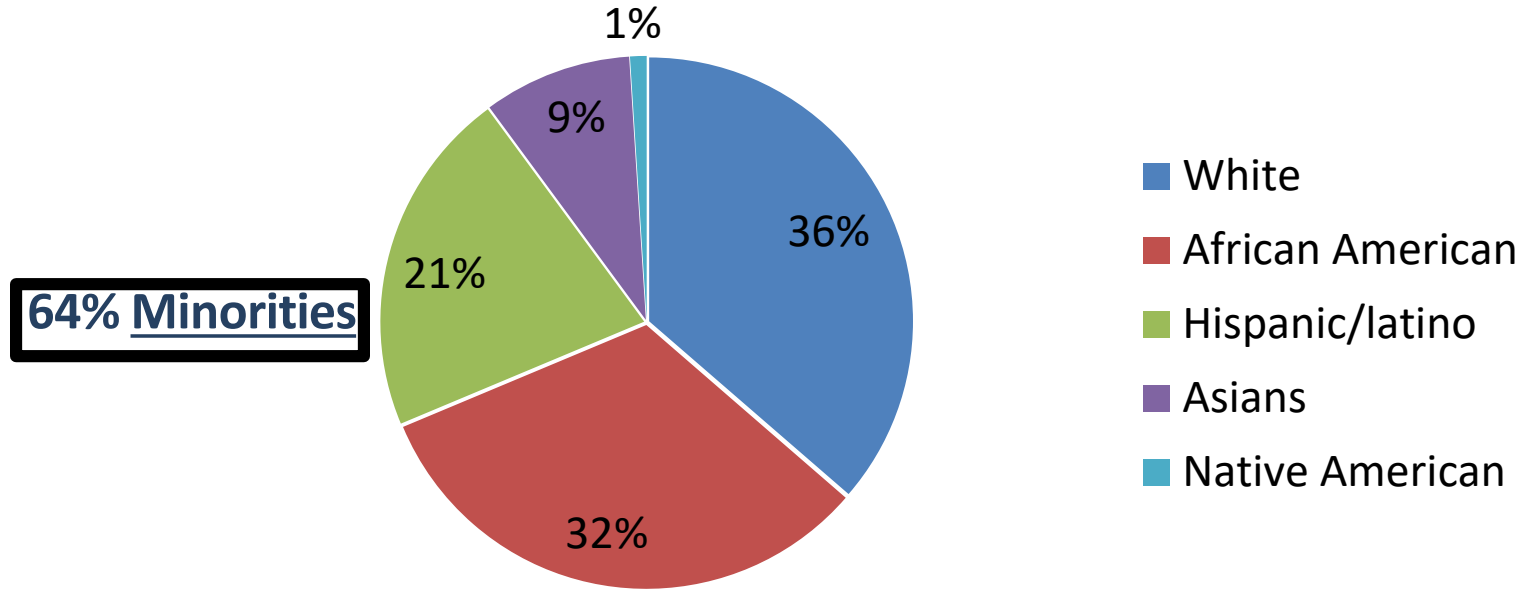
Adult Patients on the Kidney Transplant Waiting List: The Need Outweighs the Supply

Patients on the kidney transplant waiting list and numbers of kidney transplants from live and deceased donors^{1,2}



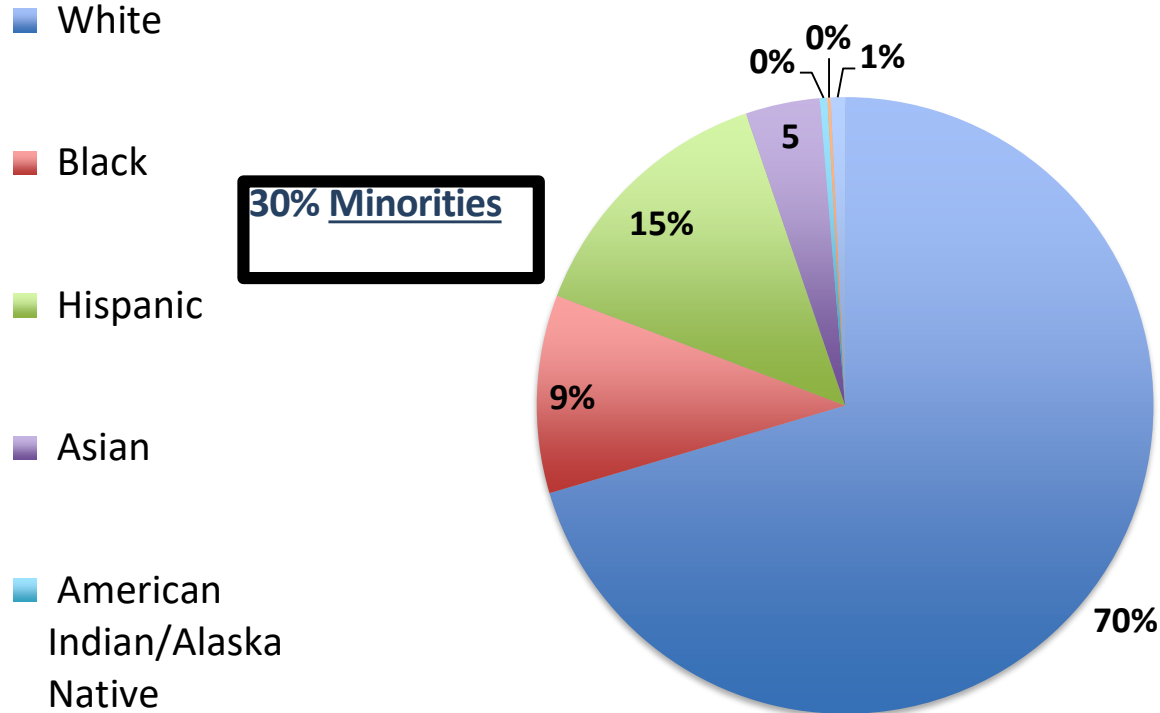
1. Hart A et al. *Am J Transplant*. 2016;16(suppl 2):11-46 [supporting information]. <http://onlinelibrary.wiley.com/doi/10.1111/ajt.13666/supinfo>. Accessed January 28, 2016. 2. Organ Procurement and Transplantation Network (OPTN). Data. <http://optn.transplant.hrsa.gov/data/>. Accessed March 8, 2016.

KIDNEY TX WAITLIST BY RACE/ETHNICITY

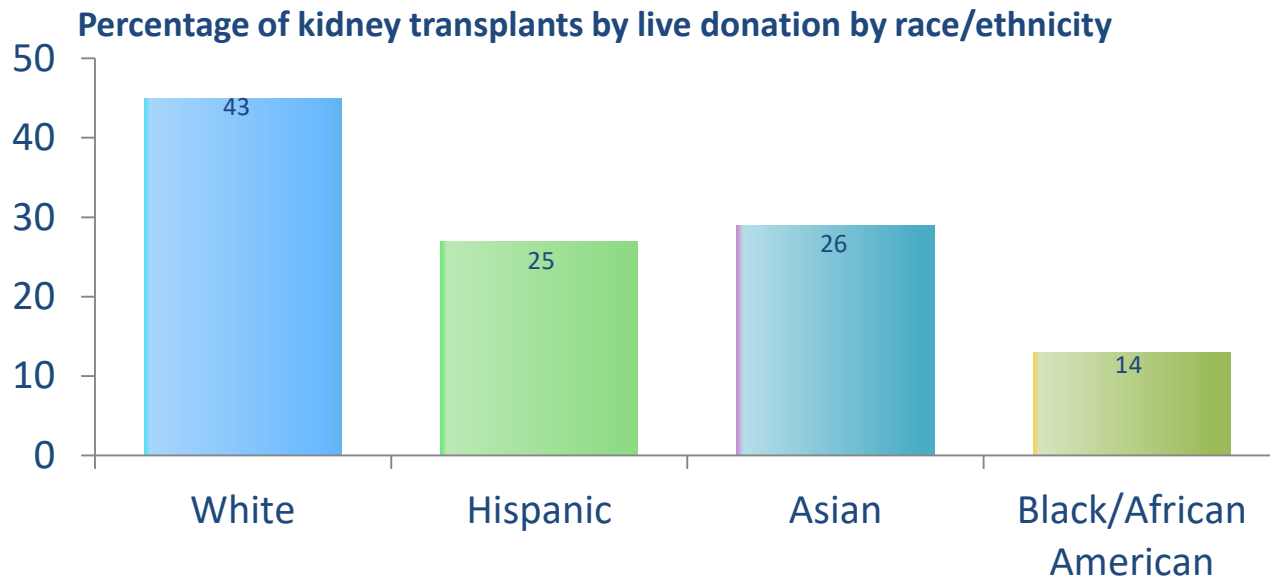


Based on OPTN data as of February 21, 2019

Living Kidney Donors by Race/Ethnicity (2018)

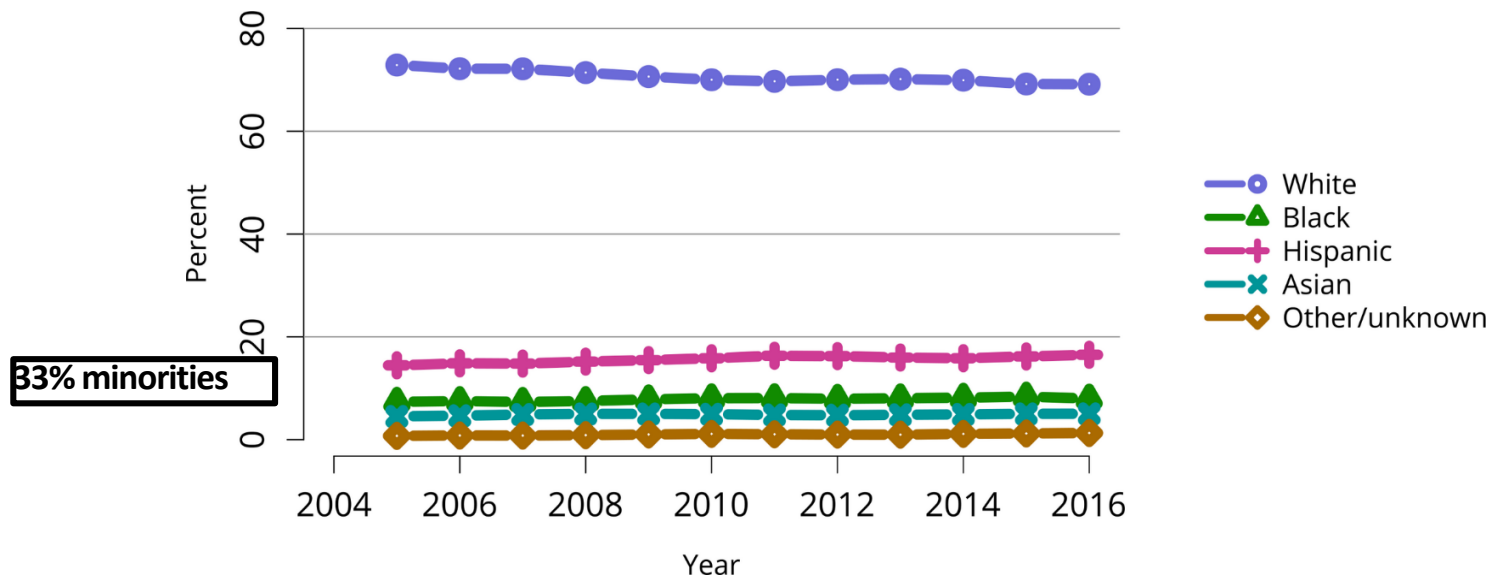


Minorities Received Fewer Kidneys From Live Donors than Whites (2018)



OPTN. Data. <http://optn.transplant.hrsa.gov/converge/latestData/rptData.asp>. Accessed February 21, 2019.

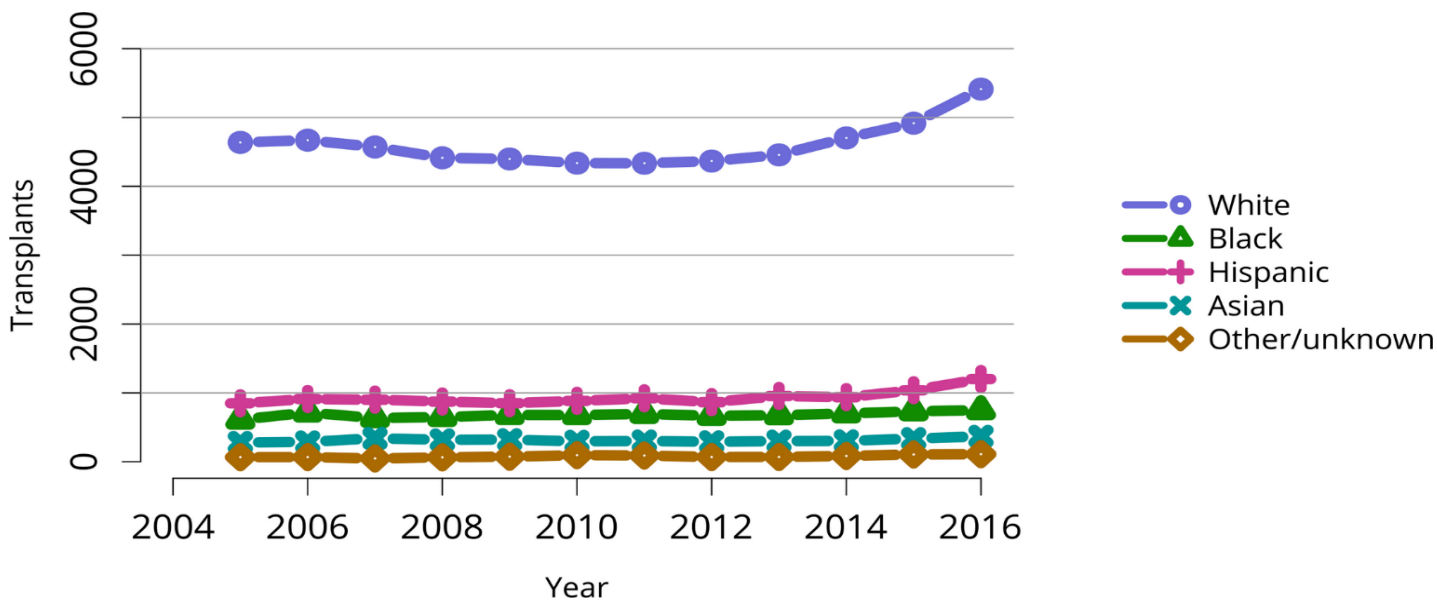
Liver waiting list by race and ethnicity



OPTN/SRTR 2016 Annual Data Report:

American Journal of Transplantation, Volume: 18, Issue: S1, Pages: 172-253, First published: 02 January 2018,

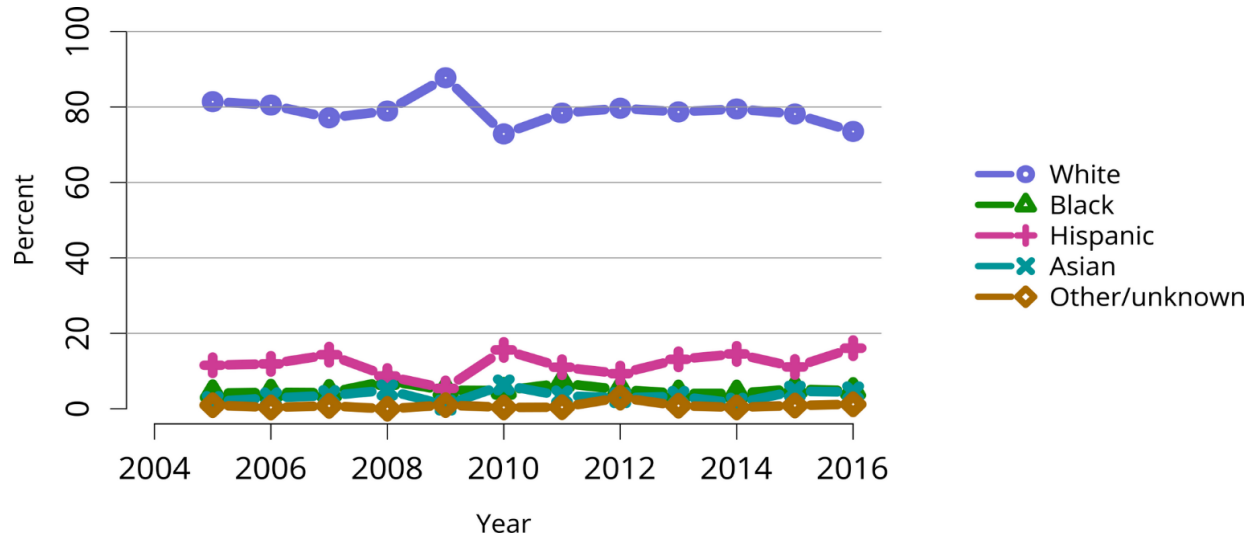
Total liver transplants by race



OPTN/SRTR 2016 Annual Data Report: Liver

American Journal of Transplantation, Volume: 18, Issue: S1, Pages: 172-253, First published: 02 January 2018

Living liver donors by race



OPTN/SRTR 2016 Annual Data Report: Liver

American Journal of Transplantation, Volume: 18, Issue: S1, Pages: 172-253, First published: 02 January 2018

Hispanic Americans and Kidney Transplantation

- Longer waiting list time when compared to non-Hispanic Whites (NHW) and African Americans (AA).
- Highest growth in kidney transplant waiting list.
- Higher waiting list mortality when compared to NHW and African Americans but same or better outcomes compared to NHW.
- Hispanics are disproportionally affected by organ shortage as they have a high prevalence of ESRD yet exhibit low rates of Living Kidney donation compared to NHW

Barriers for patients and potential living donors

- Language, including differences in dialect
- Cultural differences between patients and providers
- Distrust of providers or other individuals who do not understand the patient's culture
- Lack of community awareness
- Misconceptions about organ donation and transplantation
- Barriers impair access to preventive care, health education, and some treatment options

Are transplant programs targeting diverse populations?

Although culturally and linguistically targeted interventions could help to minimize disparities in organ donation and transplantation, there is scarcity of effective interventions and good quality internet education on living kidney donation and transplantation for minorities *

*Gordon EJ, Rodde J, Gil S, Caicedo JC. Quality of Internet education about living kidney donation for Hispanics. *J Progress in Transplantation*. 2012;22(3):294-303.

Are transplant programs targeting diverse populations? Are they using "one size fits all approach"?

Analyzed all US KTX programs 's websites (240 in 2013 and 244 in 2018)

- Website available in a language other than English: only 11 (6.3%) in 2013 and 18 (**9.7%**) in 2018 ($p=0.24$)
- Culturally tailored initiatives: 3/ 240 (1.3%) in 2013 and 7/244 (**2.9%**) in 2018 ($p= 0.23$)
- 77% of the transplant programs websites reported at least one transplant surgeon or transplant nephrologist who speaks a language other than English in 2018.
- 38% of transplant programs websites reported at least one transplant physician (surgeon or nephrologist) who speaks Spanish in 2018.*

This is a call for action to at least take advantage of the existing resources and increase the number of culturally and linguistically competent transplant programs initiatives.

* Unpublished data

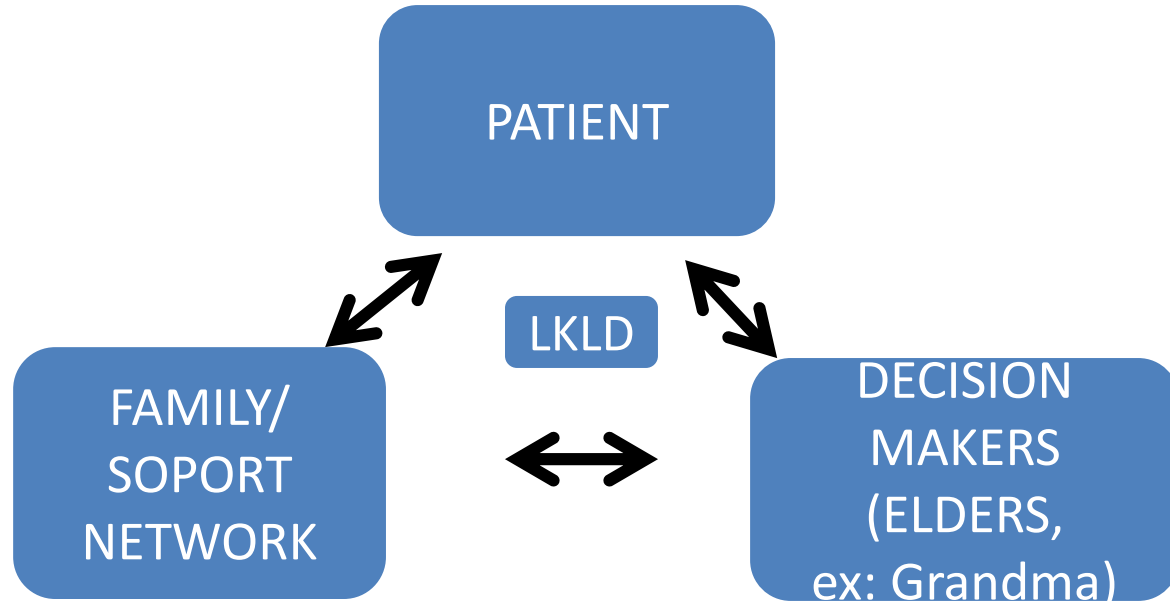
Hispanic Preferences about Transplant Education and U.S. Trends

Transplant education	Hispanic preferences *	Transplant center trends in U.S. **
Format	Language: Spanish	Language: English
	Face-to-face interaction	Written material
	Group discussion	One-on-one discussion
Educator	Physician	Non-physician (e.g., Nurse)
	Bilingual and bicultural educators No interpreters	Rely upon interpreters

***Gordon E**, Reddy E, Gil S, Feinglass J, Rodde J, Abecassis MM, **Caicedo J**. Culturally Competent Transplant Program Improves Hispanics' Knowledge and Attitudes about Live Kidney Donation and Transplantation. *Progress in Transplantation*. 2014;24(1):56-68.

****Gordon EJ**, **Caicedo JC**, Ladner DP, Reddy E, Abecassis MM. Transplant center provision of education and culturally and linguistically competent care: a national study. *American Journal of transplantation*. 2010;10(12):2701-2707.

LIVING KIDNEY / LIVER DONATION (LKLD) DECISION MAKING PROCESS



Transplant Center Based Approach to Living kidney and liver donation in Hispanic Americans (HA)

- The Northwestern Medicine developed a culturally and linguistically competent and congruent Hispanic Kidney Transplant Program (2006) and Hispanic liver transplant program (2010) as a response of the health disparities in Transplantation in HA.
- First Hispanic kidney and liver transplant program in USA.

Transplant Based Intervention: Hispanic Kidney and liver Transplant Program -Northwestern Medicine

- Bilingual and bicultural Staff team members (>20)
- Complete experience in Spanish.
- Target Hispanic patients, family and decision makers (elders)
- Face to face education (group vs one-on-one)
- Transplant Surgeon/ Hepatologist providing education
- Decrease use of translators

HISPANIC KIDNEY AND LIVER TRANSPLANT PROGRAM

To deal with the concerns preventing Hispanic families from considering living kidney /liver donation and transplantation, the Hispanic transplant program has been addressing:

language barriers, issues related to culture and education, influential role of extended family, religion, lack of knowledge, fear of donation and surgery, cultural desire to avoid harming potential donor (resulting in not asking for donation), health care professionals attitude, and financial and legal concerns

Hispanic Transplant Program Outcomes

Knowledge and Attitude towards Living kidney donation

	Before	After	p-value
Variables	Mean	Mean	<0.0001
Patients			
Knowledge(0-20)	9.86	13.05	<0.0001
Attitude (3-15)	8.7	11.07	0.004
Family/Friends			
Knowledge(0-20)	8.7	15.5	<0.0001
Attitude (8-48)	38.37	39.77	0.0014

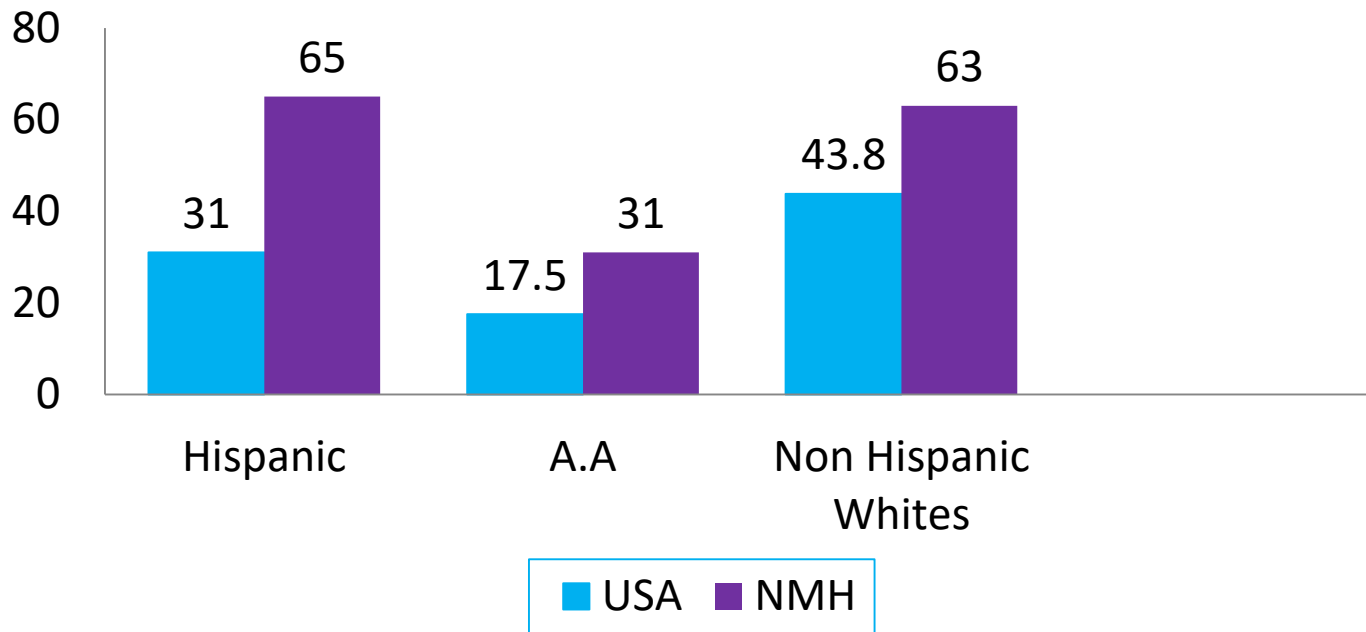
***Gordon E**, Reddy E, Gil S, Feinglass J, Rodde J, Abecassis MM, **Caicedo J**. Culturally Competent Transplant Program Improves Hispanics' Knowledge and Attitudes about Live Kidney Donation and Transplantation. *Progress in Transplantation*. 2014;24(1):56-68.

Northwestern Medicine Pre (2001-2006) vs Post (2008-2013) implementation of Hispanic kidney transplant program Mean Annual Change (%)

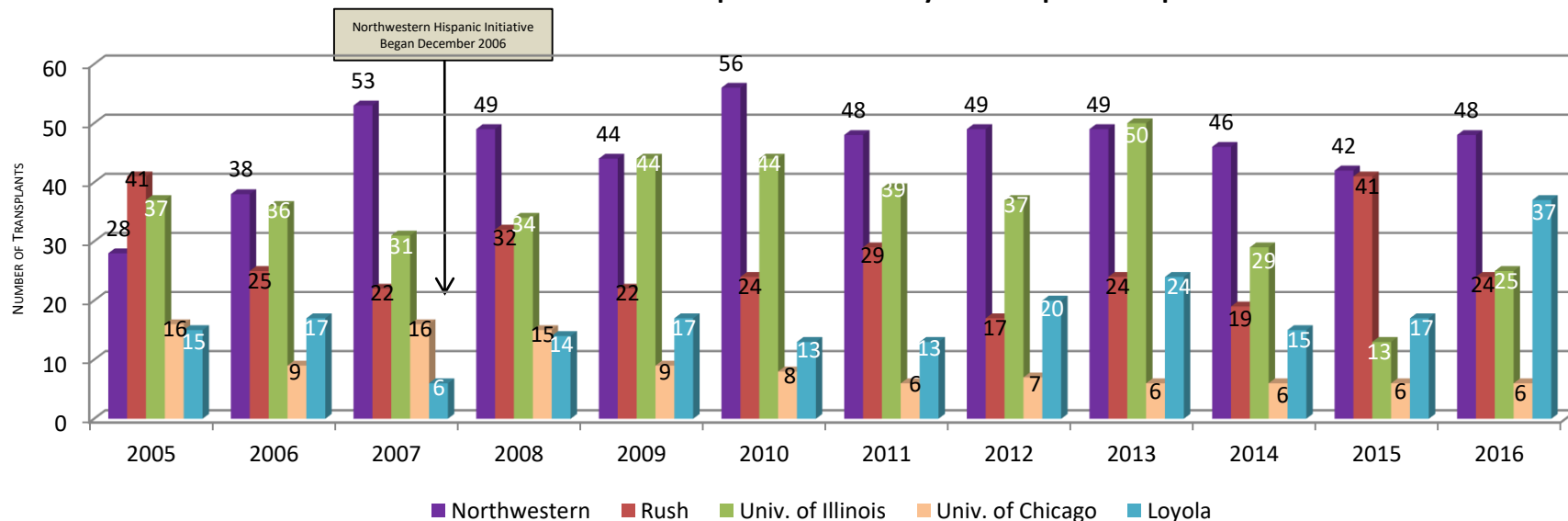
NMH: KTx: >5000, ~ 220-250 KTx/ year LDKT: #1 in USA (2012)	HISPANICS %	NON-HISPANIC WHITES %
Waitlist additions (access care, referrals patterns)	91	4
LDKT	74	6
DDKT	62	1.5
Ratio: Hispanic/NHW LDKTs (Metric of Disparity)	Pre-HKTP: 0.20, Post-HKTP: 0.34 70% Growth p<0.001	

Gordon E, Caicedo JC, et al. Transplantation Direct, Sept 2015.

Percentage of LDKTs in 2013



Since starting the **Hispanic Kidney Transplant Program** in 2006, Northwestern University Affiliated Transplant Centers (NUATC), continues to be the leader in Chicago for the number of Hispanic kidney transplants performed.



Source: UNOS.ORG Based on OPTN Data as of October 5, 2017

Northwestern University Affiliated Transplant Centers (NUATC) – Northwestern Memorial Hospital and Ann & Robert H. Lurie Children's Hospital of Chicago

TABLE 2.

Ratio of Hispanic to non-Hispanic white living donor kidney transplants by transplant center*

State	UNOS region	Center	All KTs in 2013	All LDKTs in 2013	% LDKTs in 2013	Hispanic LDKTs in 2013	% Hispanic LDKTs in 2013	Pre 2001-2006: Mean Ratio ¹	Pre 2001-2006: Ratio SD ¹	Post 2008-2013: Mean Ratio ¹	Post 2008-2013: Ratio SD ¹	P value comparing Pre and Post Mean Ratio	% Increase from Pre to Post Mean Ratio
IL	7	Northwestern Medicine	220	122	55	28	23	0.20	0.04	0.34	0.06	0.001	70
CT	1	Center 1	41	18	44	2	11	0.15	0.08	0.16	0.11	0.91	7
CT		Center 2	107	46	43	2	4	0.14	0.09	0.16	0.15	0.80	14
RI		Center 3	38	12	32	0	0	0.06	0.05	0.05	0.05	0.78	-17
NJ	2	Center 4	53	16	30	1	6	0.20	0.06	0.21	0.15	0.86	5
FL	3	Center 5	273	96	35	41	43	0.62	0.27	0.74	0.32	0.51	19
FL		Center 6	157	29	1		7	0.28	0.17	0.31	0.1		11
TX	4	Center 7	107	22	2	Hispanic LDKTs in 2013		0.29	0.10	0.28	0.1	% Increase from pre and post Mean ratio	-3
TX		Center 8	53	7	1			2.53	1.99	1.97	1.4		-22
TX		Center 9	71	27	3			0.43	0.25	0.63	0.3		47
TX		Center 10	65	11	1			0.51	0.29	0.74	0.1		45
TX		Center 11	281	187	66	22	32	1.49	0.34	1.80	0.57	0.001	21
AZ	5	Center 12	148	49	33	15	31	0.42	0.06	0.48	0.13	0.35	14
CA		Center 13	257	73	28	12	16	0.22	0.10	0.27	0.06	0.34	23
CA		Center 14	189	69	37	21	30	0.55	0.13	0.51	0.20	0.68	-7
CA		Center 15	46	4	9	1	25	2.10	0.78	6.62	3.98	0.06	215
CA		Center 16	267	110	41	35	32	0.79	0.23	0.69	0.12	0.37	-13
CA	AZ	Center 17	335	47	14	10	21	0.27	0.22	0.30	0.16	0.83	11
CA		Center 18	67	24	36	9	38	1.16	0.76	0.83	0.29	0.34	-28
CA		Center 19	71	20	28	7	35	0.50	0.15	0.71	0.18	0.06	42
IL	7	Center 20	71	14	20	7	50	0.61	0.25	0.75	0.41	0.48	23
IL		Center 21	49	14	29	2	14	0.22	0.21	0.28	0.11	0.50	27
IL		Center 22	129	78	60	31	40	1.97	0.80	1.54	0.39	0.27	-22
IL		Center 23	96	35	36	12	34	0.39	0.18	0.37	0.21	0.86	-5
CO	8	Center 24	140	40	29	6	15	0.19	0.03	0.18	0.10	0.77	-5
CO		Center 25	63	29	46	4	14	0.25	0.15	0.26	0.08	0.93	4
NY	9	Center 26	116	19	16	9	47	1.23	0.30	1.45	0.92	0.59	18
NY		Center 27	166	73	44	15	21	0.53	0.14	0.50	0.13	0.70	-6
NY		Center 28	211	106	50	33	31	0.39	0.09	0.37	0.16	0.82	-5
NY		Center 29	197	130	66	18	14	0.49	0.17	0.27	0.06	0.02	-45
United States			16,143	5453	34	802	15	0.18	0.01	0.21	0.01	<.0001	17

* Ordered by UNOS Region, Center, National.

The ratio refers to the following equation: [(Hispanic LDKT/All LDKTs) / (non-Hispanic white LDKT/All LDKTs)]. The mean ratio refers to the mean over each year within the given time period.

Centers in top tertile of adult LDKT volume in areas with >25% Hispanics

Gordon E, Caicedo JC, et al. Transplantation Direct, Sept 2015.

We can make a national impact!

HKTP Adoption rate, %	# Additional Hispanic LDKTs nationally per year, if each center adds 5-10 LDKTs	% Annual national Increase in Hispanic LDKTs**
0%	0	0.6%**
10%	84-174	11%-22%
20%	174-348	22%-44%
30%	261-522	33%-66%

*Denominator is based on 174 centers that perform LDKTs and serve a large Hispanic population.

**Based on the last 10 years of annual mean number of Hispanic LDKTs in the U.S. (2004-2013) (n=784).

NORTHWESTERN MEDICINE

HISPANIC LIVER TRANSPLANT PROGRAM (HLTP)

HLTP (2002-2009) vs Post HLTP (2011-2018)

Mean Annual Change (%)

NMH= ~2000, 100-120 LTx/y 2014 :#1 in USA : LDLT (NUATC)	HISPANICS		NON HISPANIC WHITES	
	NORTHWESTERN %	USA %	NORTHWESTERN %	USA %
Waitlist additions (~ access care, referrals patterns)	<u>54</u>	25	-22	13
Liver transplants	<u>54</u>	28	-7	13
LDLT	<u>88</u>	13	-23	5
DDLT	<u>51</u>	29	-4	13

CONCLUSIONS

- Culturally targeted transplant program can increase patients and families' knowledge about Living kidney donation (LKD), and increase favorable attitudes toward LKD, perhaps contributing to the increased number of potential donors initiating evaluation, and number of LDKTs.
- Culturally sensitive strategies can help to reduce LDKT disparities in Hispanics
- Similar strategies can be applied to other organs (Liver) and may be useful for other ethnic/ racial groups.



Questions??

Thank you!

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