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# **The Transplant Waiting List and Organ Allocation Process**

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**2013 Douglas T. Miller Symposium  
on Organ Donation and Transplantation  
Thursday, April 25, 2013**

# Presentation Objectives:

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- Gain knowledge of state, regional, and national statistics related to the transplant waiting list and transplantation.
- Develop an understanding of the complexities surrounding being on the transplant waiting list and the medical reasons why a patient is added to the transplant waiting list.
- Hear and understand the emotional and physical constraints of being on a transplant waiting list, waiting for the call, and being given a second chance at life.

# Waiting List Data and Statistics

## ■ UNOS: United Network for Organ Sharing

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## ■ OPTN: Organ Procurement and Transplantation Network

OPTN: Organ Procurement and Transplantation Network

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Uniting people and information to help save lives

The Organ Procurement and Transplantation Network (OPTN) maintains the only national patient waiting list and features comprehensive data available in any single field of medicine. [Learn More About the OPTN >>](#)

### Data

Waiting list candidates 117,942 as of today 3:49pm

[Active](#) waiting list candidates 75,039 as of today 3:49pm

Transplants January - January 2013 2,313 as of 04/12/2013

Donors January - January 2013 1,150 as of 04/12/2013

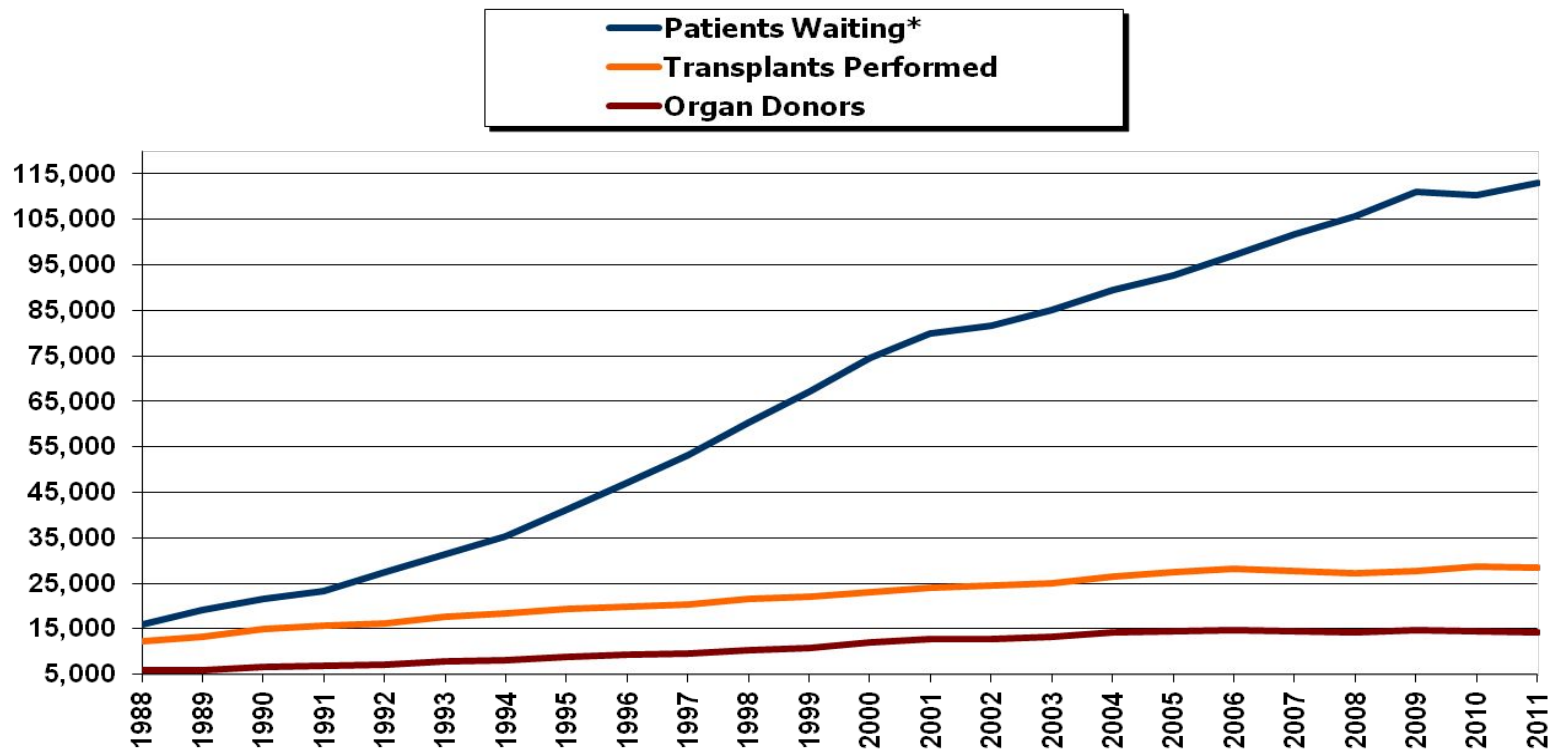
### Calendar

[April 14 - 20, 2013](#)

- OPTN/UNOS Policy Oversight Committee Meeting
- OPTN/UNOS OPO Committee Meeting
- 21st Annual UNOS Transplant Management Forum
- OPTN/UNOS Region 8 Meeting

Source: UNOS/OTPD.net, 4/5/13

# “The Gap”



\*Data based on snapshot of the UNOS, OPTN waiting list and transplants on the last day of each year.

# Waiting Lists

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- National
- Regional
- Local
- Center

# U.S. Waiting List Data and Statistics

## Overall by Organ

Current U.S. Waiting List

For Format = Portrait

Based on OPTN data as of April 5, 2013

Page 1 of 1

Change Report (Optional) :

[Create a New Report](#)

Count

Registration

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Heart / Lung	Intestine
Candidates	117,615	95,846	15,761	1,185	2,147	3,498	1,682	49	261

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portrait landscape

Data subject to change based on future data submission or correction. Totals may be less than the sums due to patients included in multiple categories.

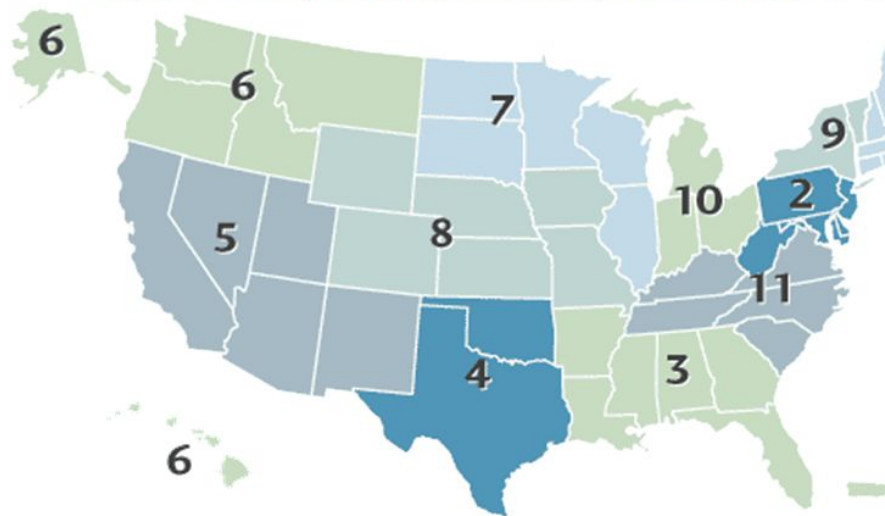
Source: UNOS/OTPD.net, 4/5/13

# Regional Waiting List Data and Statistics



Step 1: Choose a Region  or click the map below :

Region 7 : Illinois, Minnesota, North Dakota, South Dakota, Wisconsin



## Region 7

State	OPO	TXC
Illinois	1	9
Minnesota	1	5
North Dakota	0	2
South Dakota	0	2
Wisconsin	2	5

OPO : Organ


Procurement Org.

TXC : Transplant Center

Source: UNOS/OTPD.net, 4/5/13



# Regional Waiting List Data and Statistics

Font Size: 

## Overall by Organ

Current U.S. Waiting List  
For Area = Region 7, Format = Portrait  
Based on OPTN data as of April 5, 2013

Page 1 of 1






## Change Report (Optional) :

[Create a New Report](#)

Count Region  
Registration  Region 7  

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Heart / Lung	Intestine
Candidates	10,460	8,529	1,255	209	308	413	159	1	13

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Data subject to change based on future data submission or correction. Totals may be less than the sums due to patients included in multiple categories.

Source: UNOS/OTPD.net, 4/5/13



# WI Waiting List Data and Statistics

## Overall by Organ

Page 1 of 1

Current U.S. Waiting List

For Area = Wisconsin, Format = Portrait

Based on OPTN data as of April 5, 2013



## Change Report (Optional) :

[Create a New Report](#)

Count State  
 Registration Wisconsin Go

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Intestine
Candidates	2,110	1,743	243	10	49	70	38	1

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Data subject to change based on future data submission or correction. Totals may be less than the sums due to patients included in multiple categories.

Source: UNOS/OTPD.net, 4/5/13

# MI Waiting List Data and Statistics

## Overall by Organ

Page 1 of 1

Current U.S. Waiting List

For Area = Michigan, Format = Portrait

Based on OPTN data as of April 5, 2013



## Change Report (Optional) :

[Create a New Report](#)

Count

State

Registration ▼

Michigan ▼

Go

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landscape

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Intestine
Candidates	3,169	2,638	351	19	46	81	84	7

Data subject to change based on future data submission or correction. Totals may be less than the sums due to patients included in multiple categories.

Source: UNOS/OTPD.net, 4/5/13

# IL Waiting List Data and Statistics

## Overall by Organ

Page 1 of 1

Current U.S. Waiting List

For Area = Illinois, Format = Portrait

Based on OPTN data as of April 5, 2013



## Change Report (Optional) :

[Create a New Report](#)

Count	State
Registration ▼	Illinois ▼
<input type="button" value="Go"/>	

	All Organs	Kidney	Liver	Pancreas	Kidney / Pancreas	Heart	Lung	Intestine
Candidates	5,168	4,460	462	53	86	174	58	11

count flip print

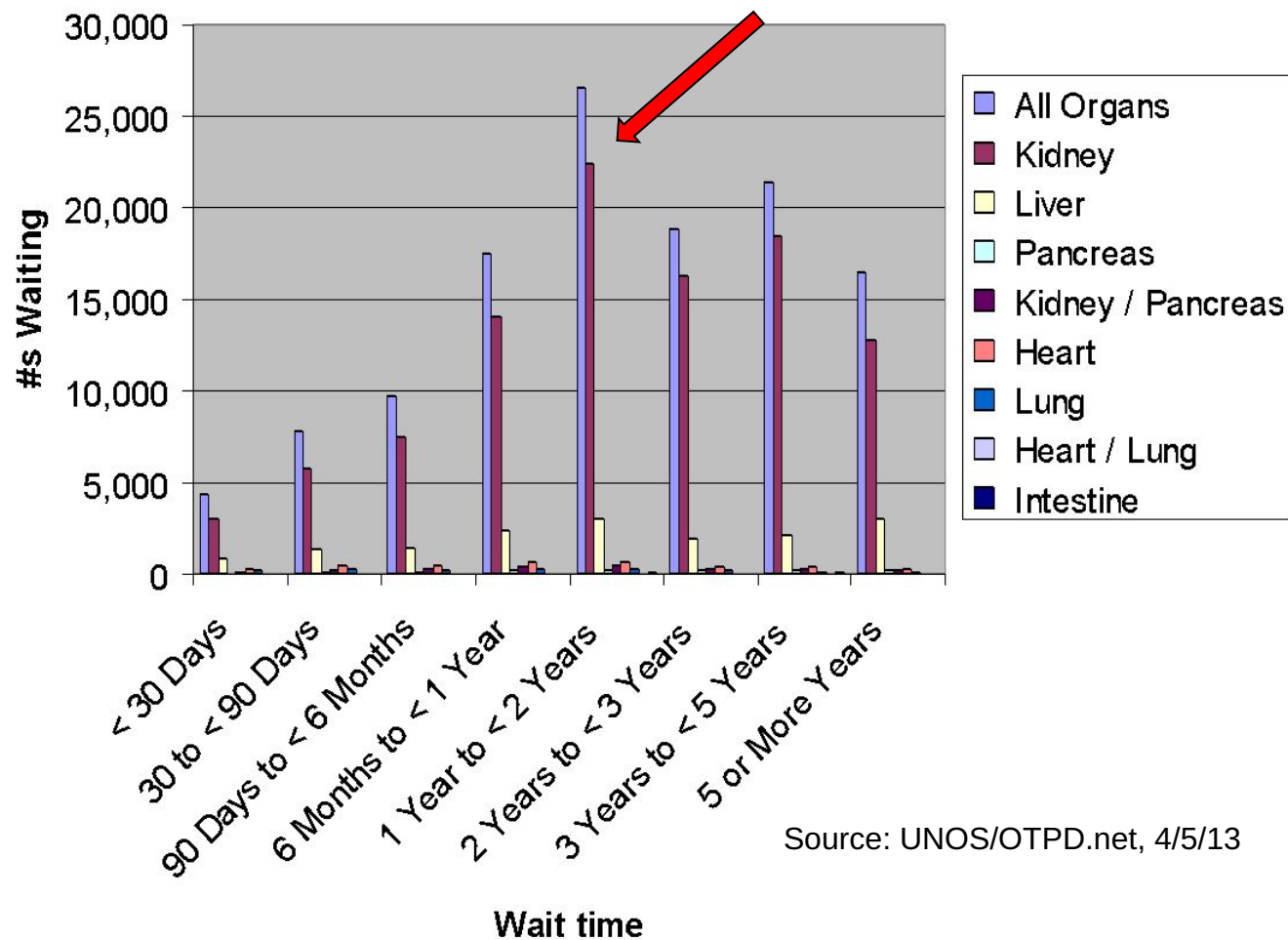
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Data subject to change based on future data submission or correction. Totals may be less than the sums due to patients included in multiple categories.

Source: UNOS/OTPD.net, 4/5/13

# How long does the typical waitlisted patient wait for a transplant?



Source: UNOS/OTPD.net, 4/5/13



# UW OTD's Laura Van Drese: Her Dad's Story



# UW Average Waiting Times

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## Deceased Donor Kidney Transplants

- Wait Time by Blood Type

(Includes patients transplanted between 7/1/2010 - 6/30/2012)

<b>ABO</b>	<b>Average days</b>
A	315
AB	286
B	684
O	811



# Necessary Steps to Getting on the Center Waiting List

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- Your physician must give you a referral
- Contact a transplant hospital
- Schedule an appointment for an evaluation and find out if you are a good candidate for transplant
- If the hospital's transplant team determines that you are a good transplant candidate, they will add you to the national waiting list

# Evaluation

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- Schedule Evaluation Appointment
  - Surgeon
  - Social Work
  - Certified Dietician
  - Financial Counselor
  - Pre-Transplant Coordinator
  
- Further Testing
  - Chest X-ray
  - Blood Work
  - Other

# Standard Evaluation Testing

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- Colonoscopy age >50
- Mammogram and Pap Smear Annually
- PSA age>50
- Chest X-ray
- Dental Clearance
- Cardiac Testing
- Vascular Testing

# Approval

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- Multi-Disciplinary Committee Review
  - Significant Coronary Artery Disease
  - Significant Vascular Disease
  - Malignancy
  - Non-Compliance
  - Substance Abuse (Active)
  - Poor Social/Financial Support
- Insurance Approval

# Two Types of Transplantation

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- Deceased Donor: UNOS Waiting list, UWHC Waiting List
- Live Donor: can be related or non-related
  - related by blood or marriage
  - non-related directed donation
  - humanitarian non-directed donor donation
  - National Kidney Paired Exchange Program

# Waiting: Complexities and Constraints

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- Medical Preparation
  - stay healthy
  - keep your appts
- Practical Preparation
  - stay organized
  - phone/email tree
  - pack your bags
  - dependant care
  - transportation plan
- Educational Preparation
  - learn, read, find a support group
- Financial Preparation
  - create financial plan
  - talk to your family
  - POA
- Spiritual Preparation
  - seek spiritual help or counseling.
- Receiving “the call”
  - ALWAYS answer your phone
  - have directions to transplant center ready



# Personal Constraints: Physical and Emotional

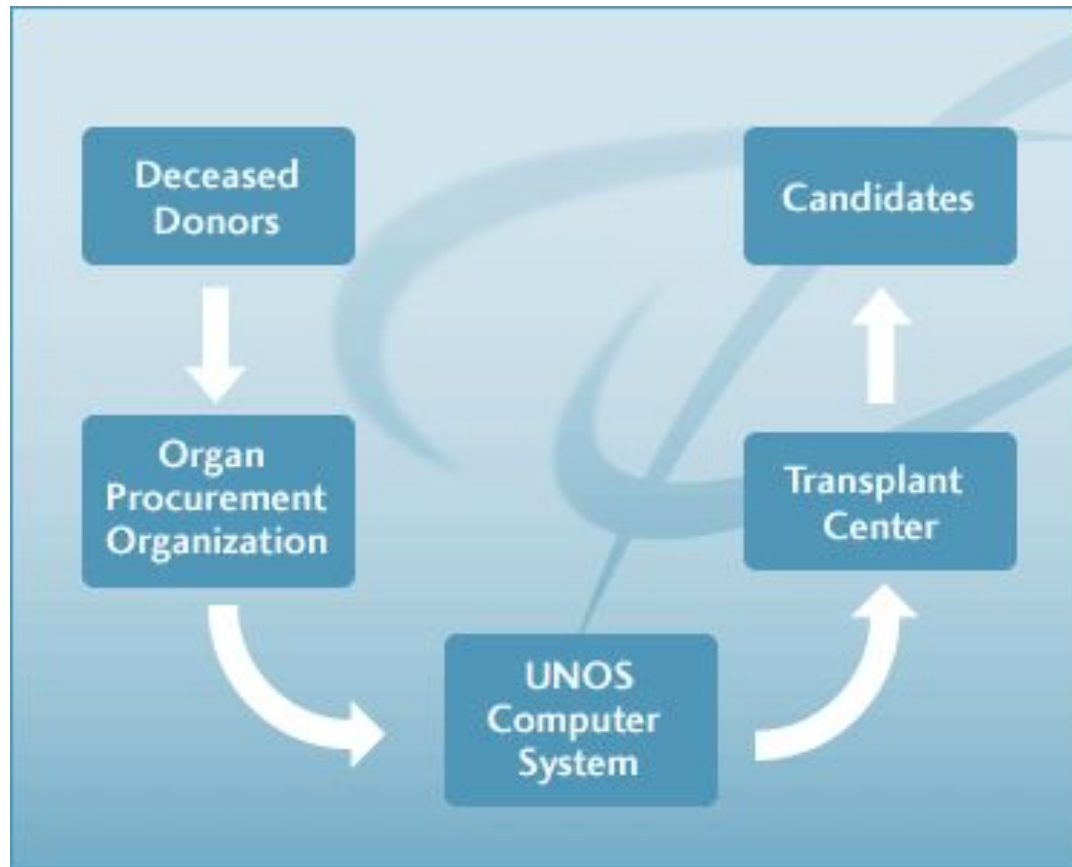
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- “I was at the top of the liver waiting list, too sick to be home with my family. While at the hospital, my doctor said, ‘you have to eat’, but I couldn’t keep anything down, so they had to put a feeding tube in. Try taking twenty pills a day with a feeding tube down your throat. It was awful.”  
Lee Belmas, Liver Recipient

- “My original diagnosis was Type 1 Diabetes. I just assumed I would die at a young age. After my transplant, I felt like the windows of my house blew wide open. I saw brighter colors, a sense of hope, light, and excitement.”  
Nancy Garde, Kidney/Pancreas Recipient

# Allocation: Matching Donor Organs With Transplant Candidates

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Source: UNOS.org/TransplantLiving.org, 4/5/13

# “Match Run”

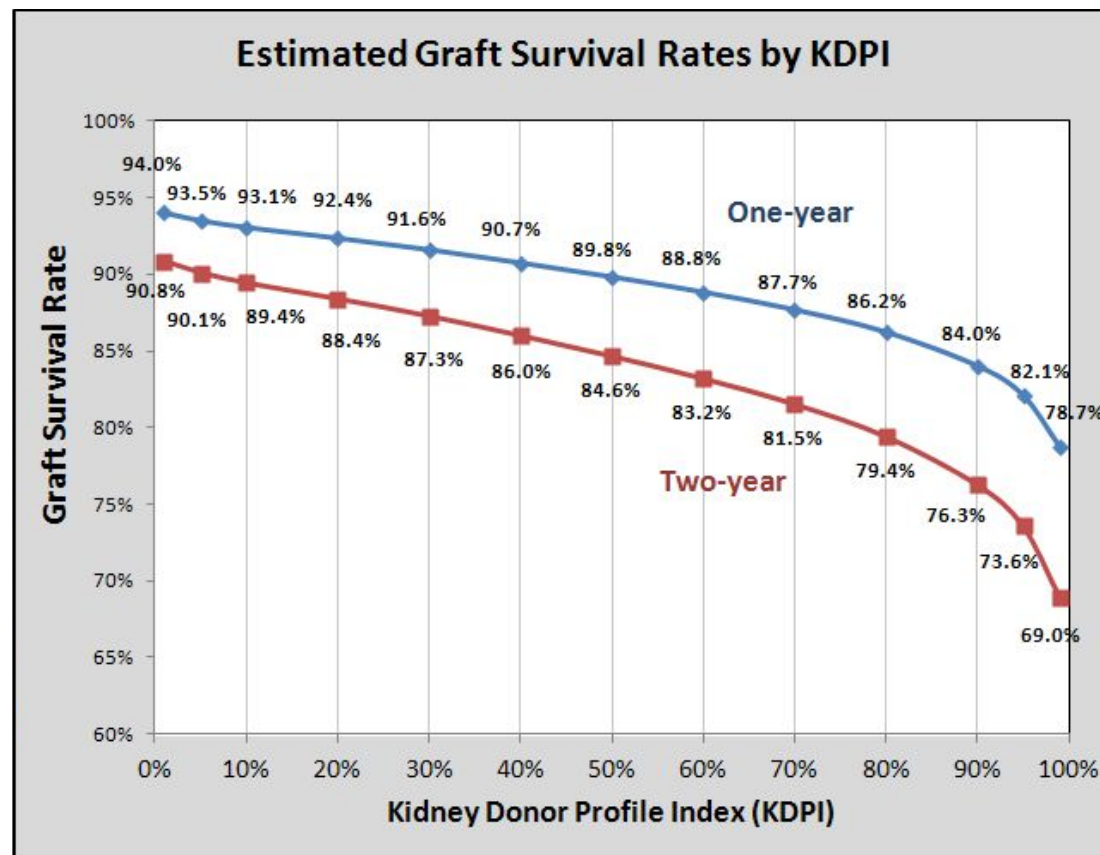
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- Factors affecting ranking may include:
  - tissue match
  - blood type
  - length of time on the waiting list
  - immune status - sensitization
  - donor organ quality
  - distance between the potential recipient and the donor
  - degree of medical urgency (for heart, liver, lung and intestines)

# Kidney Donor Profile Index (KDPI)

## KDPI Variables

- Donor age
- Height
- Weight
- Ethnicity
- History of Hypertension
- History of Diabetes
- Cause of Death
- Serum Creatinine
- HCV Status
- DCD Status



*KDPI values now displayed with all organ offers in DonorNet®*

# **Inclusion of Longevity Matching**

- Current system does not include measure of potential longevity with transplant
- Longevity matching for some candidates could reduce the need for repeat transplants

# **Inclusion of Longevity Matching**

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- Four medical factors used to calculate Estimated Post Transplant Survival (EPTS)
  - Age
  - History of diabetes
  - Length of time on dialysis
  - History of a prior transplant



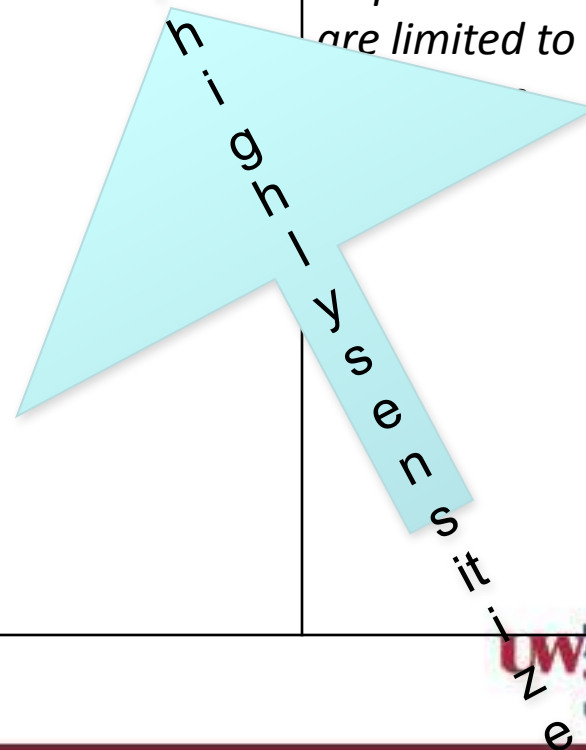
# Proposed Classifications: *Very Highly Sensitized*

- Candidates with CPRA  $\geq 98\%$  face immense biological barriers
- Current policy only prioritizes sensitized candidates at the local level.
- Proposed policy would give following priority

CPRA=100%	National
CPRA=99%	Regional
CPRA=98%	Local

- To participate in Regional/National sharing, review & approval of unacceptable antigens will be required

Sequence A KDPI ≤20%	Sequence B KDPI >20% but <35%	Sequence C KDPI ≥35% but ≤85%	Sequence D KDPI>85%
Highly Sensitized O-ABDRmm (top 20% EPTS) Prior living donor Local pediatrics Local top 20% EPTS O-ABDRmm (all) Local (all) Regional pediatrics Regional (top 20%) Regional (all) National pediatrics National (top 20%) National (all)	Highly Sensitized O-ABDRmm Prior living donor Local pediatrics Local adults Regional pediatrics Regional adults National pediatrics National adults	Highly Sensitized O-ABDRmm Prior living donor Local Regional National	Highly Sensitized O-ABDRmm Local + Regional National <i>*all categories in Sequence D are limited to adult</i>

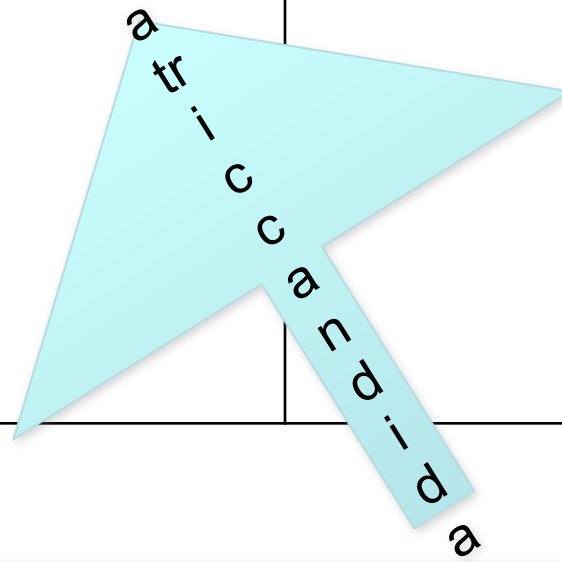


# Modified Classification: *Pediatric*

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- Current policy prioritizes donors younger than 35 to candidates listed prior to 18<sup>th</sup> birthday
- Proposed policy would
  - Prioritize donors with KDPI scores <35%
  - Eliminate pediatric categories for non 0-ABDR KPDI >85%
- Provides comparable level of access while streamlining allocation system

Sequence A KDPI ≤20%	Sequence B KDPI >20% but <35%	Sequence C KDPI ≥35% but ≤85%	Sequence D KDPI>85%
Highly Sensitized O-ABDRmm (top 20% EPTS) Prior living donor Local pediatrics Local top 20% EPTS O-ABDRmm (all) Local (all) Regional pediatrics Regional (top 20%) Regional (all) National pediatrics National (top 20%) National (all)	Highly Sensitized O-ABDRmm Prior living donor Local pediatrics Local adults Regional pediatrics Regional adults National pediatrics National adults	Highly Sensitized O-ABDRmm Prior living organ donor Local Regional National	Highly Sensitized O-ABDRmm Local + Regional National <i>*all categories in Sequence D are limited to adult candidates</i>



# **Modified Classification:** ***Local + Regional for High KDPI Kidneys***

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- KDPI >85% kidneys would be allocated to a combined local and regional list
- Would promote broader sharing of kidneys at higher risk of discard
- DSAs with longer waiting times are more likely to utilize these kidneys than DSAs with shorter waiting times

<b>Sequence A</b> <b>KDPI ≤20%</b>	<b>Sequence B</b> <b>KDPI &gt;20% but &lt;35%</b>	<b>Sequence C</b> <b>KDPI ≥35% but ≤85%</b>	<b>Sequence D</b> <b>KDPI &gt;85%</b>
<p>Highly Sensitized O-ABDRmm (top 20% EPTS) Prior living organ donor Local pediatrics Local top 20% EPTS Local (all) Regional pediatrics Regional (top 20%) Regional (all) National pediatrics National (top 20%) National (all)</p>	<p>Highly Sensitized O-ABDRmm Prior living organ donor Local pediatrics Local adults Regional pediatrics Regional adults National pediatrics National adults</p>	<p>Highly Sensitized O-ABDRmm Prior living organ donor Local Regional National</p>	<p>Highly Sensitized O-ABDRmm <b>Local + Regional</b> National <i>*all categories in Sequence D are limited to adult candidates</i></p>

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# Removed Classification: *Kidney Paybacks*

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- Current payback policy was evaluated and found to be
  - Administratively challenging
  - Unfair in that it affected all candidates in an OPO even if only one center was responsible for accruing debt
  - Ineffective in improving outcomes of recipients
- Kidney paybacks would no longer be permitted.
- All payback credits and debts would be eliminated upon the implementation of the revised kidney allocation system.

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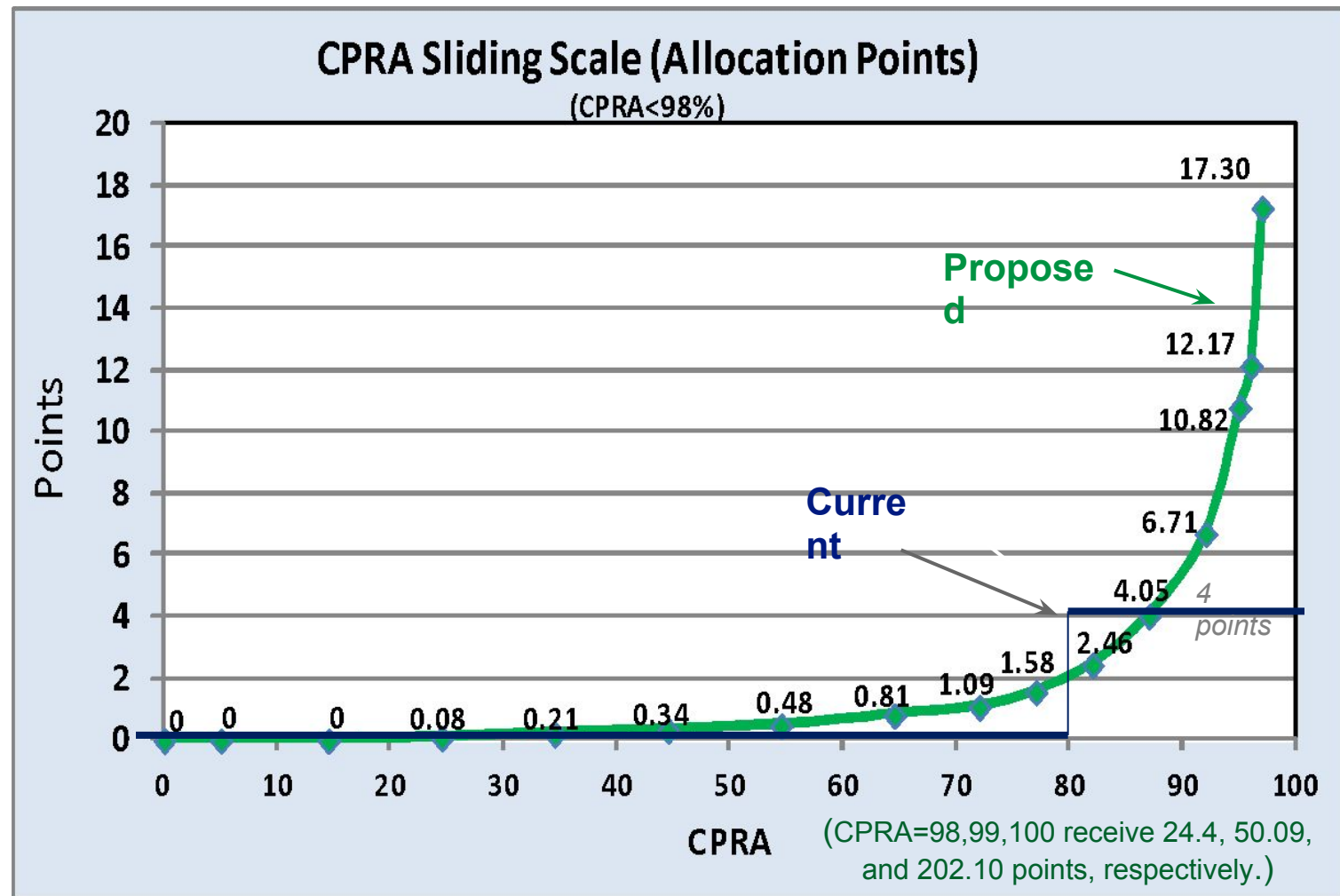
# PRIORITY WITHIN CLASSIFICATIONS

# Proposed Changes to Point System

- *Candidates are rank-ordered according to points within each classification.*

No proposed point changes for	Proposed point changes for
<ul style="list-style-type: none"><li>• HLA-DR</li><li>• Prior living organ donors</li><li>• Pediatric candidates</li></ul>	<ul style="list-style-type: none"><li>• Sensitized candidates</li><li>• Waiting time</li></ul>

# Proposed Point Changes: *Sensitization*



- Current policy: 4 points for CPRA ≥ 80%. No points for moderately sensitized candidates. Proposed policy: sliding scale starting at CPRA ≥ 20%

# Proposed Point Changes: *Waiting Time*

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- Current policy begins waiting time points for adults at registration with:
  - $GFR \leq 20$  ml/min
  - Dialysis time
- Proposed policy would also award waiting time points for dialysis time prior to registration
  - Better recognizes time spent with ESRD as the basis for priority
- Pre-emptive listing would still be advantageous for O-ABDR mismatch offers

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# **SIMULATED POLICY RESULTS**

# Evaluating Potential Policy Changes

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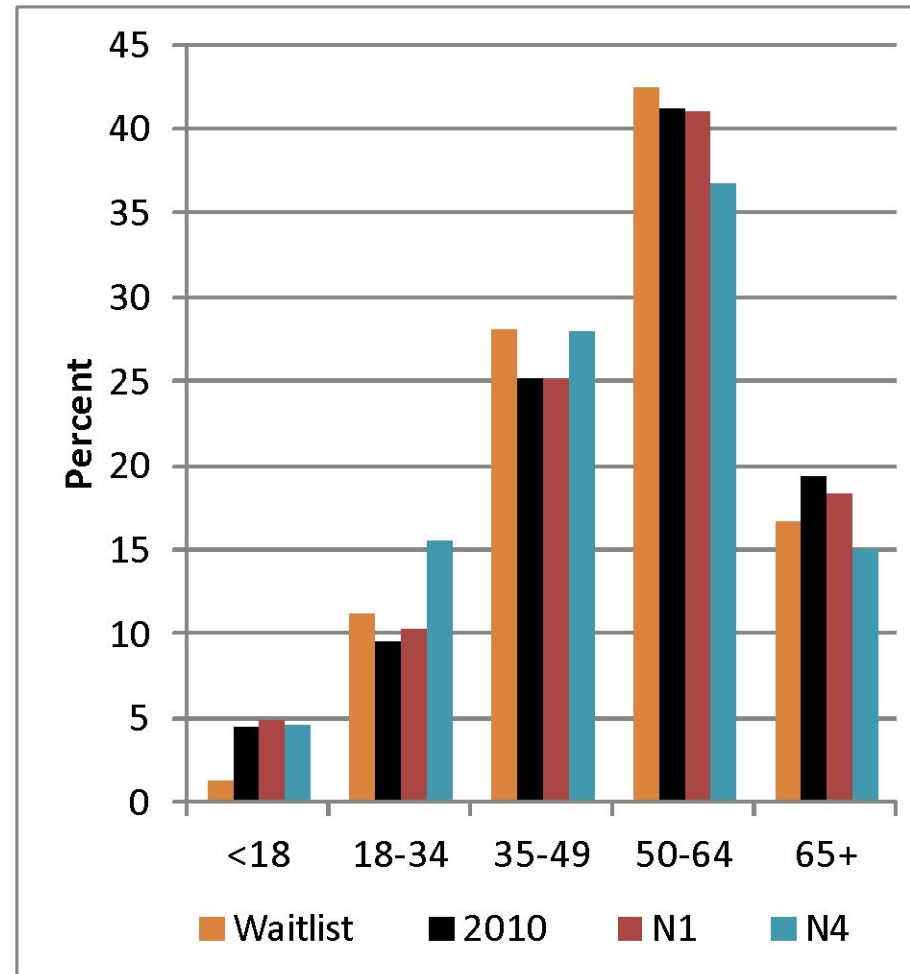
- Scientific Registry of Transplant Recipients (SRTR) simulates proposed policy changes
- Kidney-Pancreas Simulated Allocation Model (KPSAM)
- 50+ KPSAM runs conducted throughout policy development
- 4 KPSAM runs presented here for comparison

# Preview of Expected Outcomes

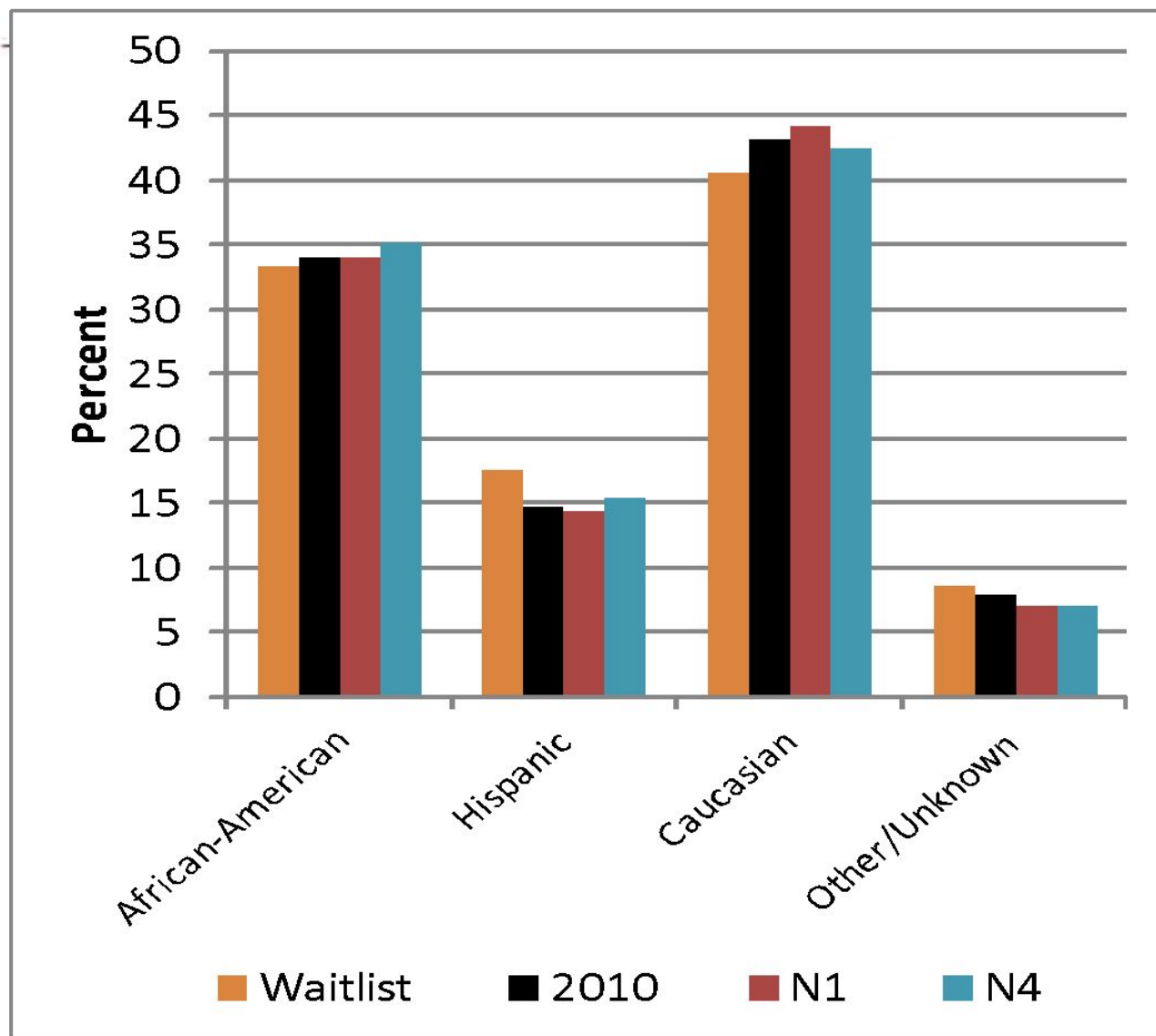
- New system forecasted to result in:
  - 8,380 additional life years gained annually
  - Improved access for moderately and very highly sensitized candidates
  - Improved access for ethnic minority candidates
  - Comparable levels of kidney transplants at regional/national levels



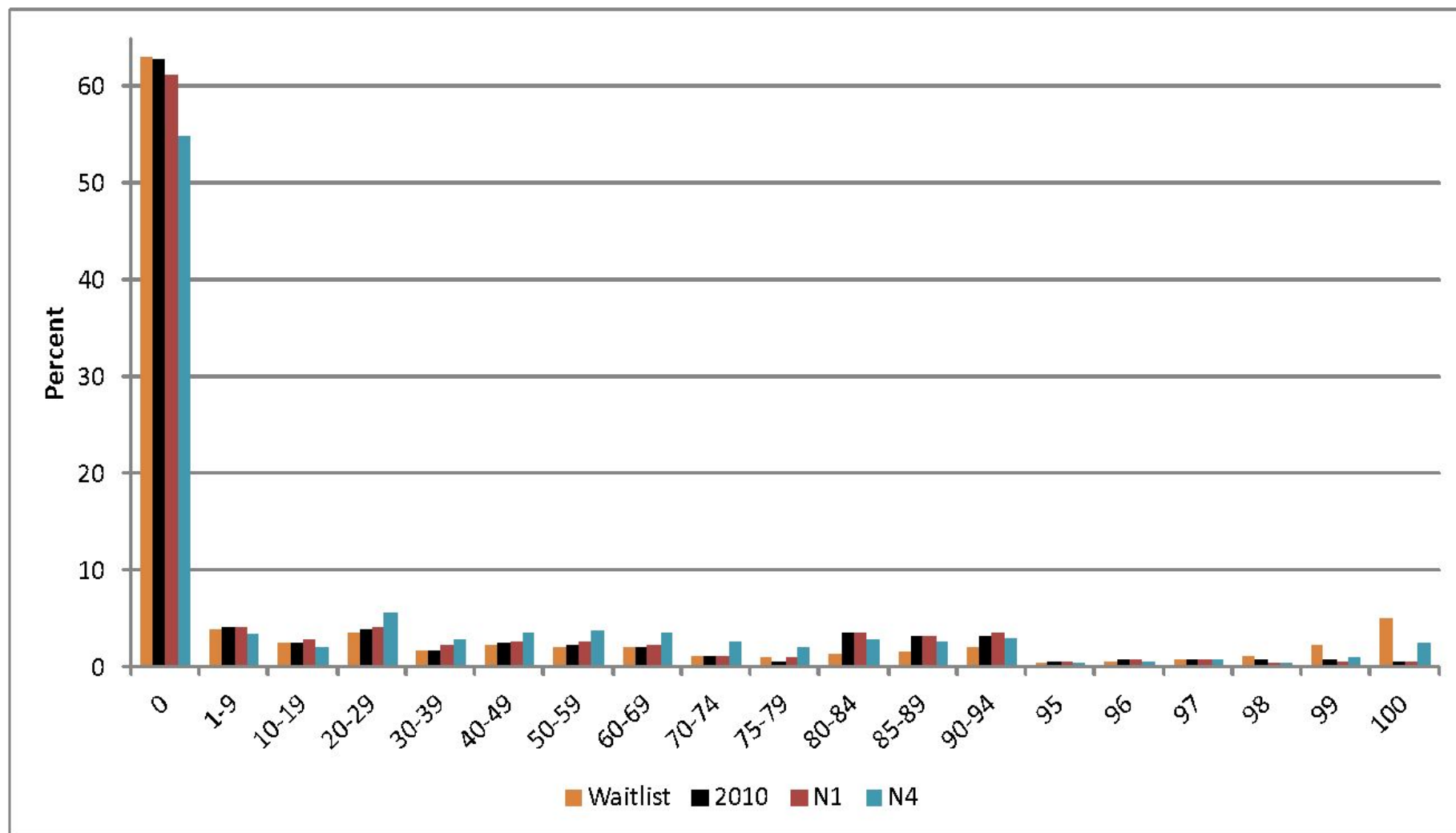
# KPSAM results by candidate age



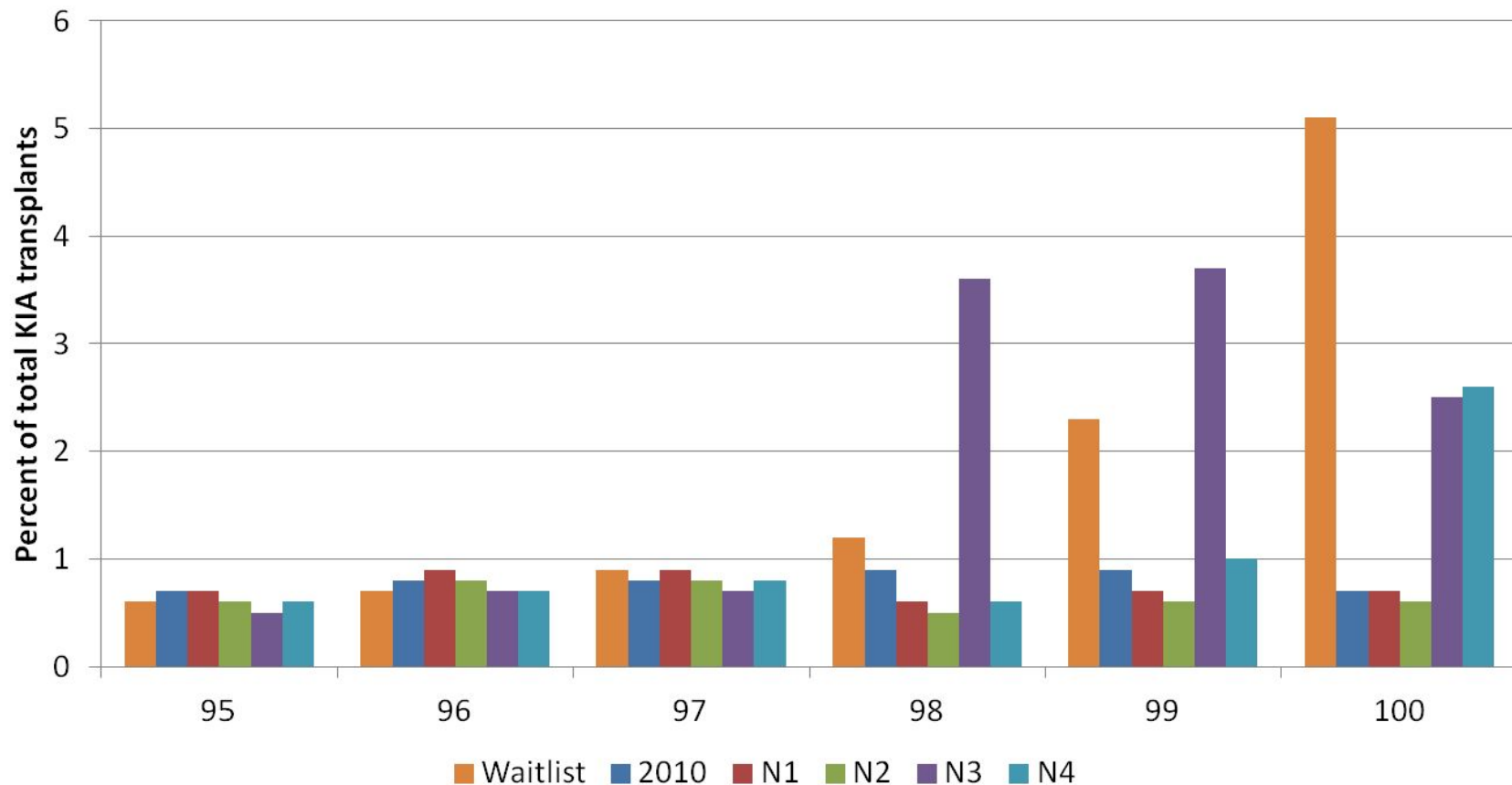
# KPSAM results by ethnicity



# KPSAM results by CPRA



# KPSAM results by CPRA (95-100%)



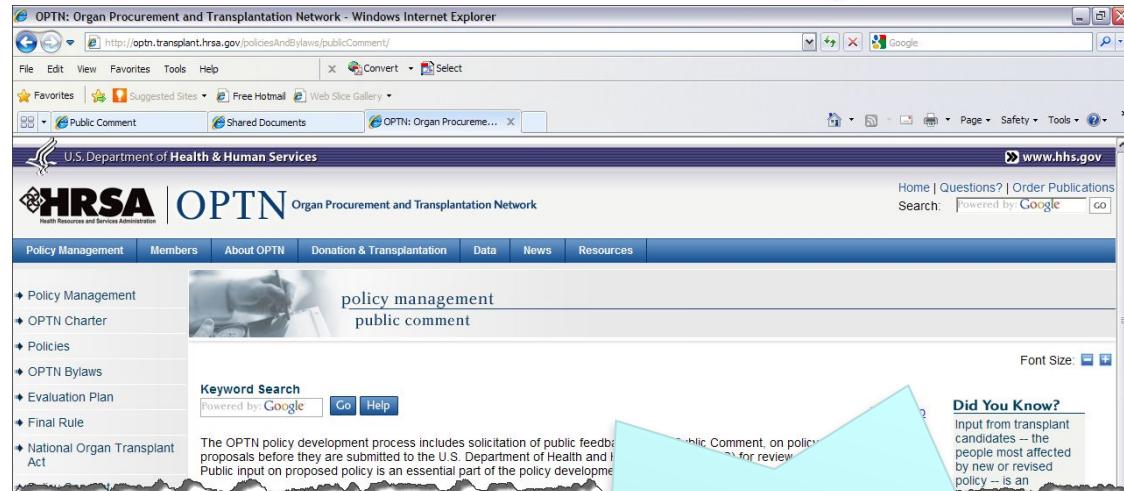
# Summary

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- New system forecasted to result in:
  - 8,380 additional life years gained annually
  - Improved access for moderately and very highly sensitized candidates
  - Improved access for ethnic minority candidates
  - Comparable levels of kidney transplants at regional/national levels

# Participate in Policy Development

- Submit comments online:  
[optn.transplant.hrsa.gov](http://optn.transplant.hrsa.gov)
- Access webinar schedules
- Download educational materials



**Public  
comment period  
ends December 14**

# Committee Leadership and Support

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- **John J. Friedewald, MD**  
Committee Chair
- **Richard N. Formica, Jr, MD**  
Committee Vice Chair
- **Ciara J. Samana, MSPH**  
UNOS Committee Liaison  
[ciara.samana@unos.org](mailto:ciara.samana@unos.org)  
804-782-4073

# UW OTD Services

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“Connect to Purpose Letter”





**Don't Take Your Organs to Heaven  
Heaven Knows We Need Them Here**