

# OPPAGA Review of Florida's Organ Donation and Transplantation System

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Presentation to the Senate Committee on Health Policy

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# OPPAGA

Office of Program Policy Analysis and Government Accountability

JANUARY 28, 2020

# Project Scope

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OPPAGA examined Florida's organ donation and transplantation system and addressed the following

- Description of the organ donation and transplantation system
- Florida's performance in donor registration over time
- Projected impact on Florida of changes to national organ allocation policies
- Factors that enhance organ transplant success
- Challenges associated with organ donation and transplantation in Florida
- Legislation other states have passed to improve organ availability
- Options the Legislature could consider to improve organ availability in Florida

# Roles of Federal Entities in the Organ Donation and Transplantation System



## Federal Entities

### U.S. Department of Health and Human Services

- Oversees the two federal agencies responsible for regulating organ procurement and transplantation (CMS & HRSA)

### Centers for Medicare and Medicaid Services (CMS)

- Monitors procurement and transplant program success and quality

### Health Resources and Services Administration (HRSA)

- Oversees the Organ Procurement and Transplantation Network and contractors (United Network for Organ Sharing and Scientific Registry of Transplant Recipients)



## Private/Nonprofit Entities

### Organ Procurement and Transplantation Network (OPTN)

- Maintains a national registry for organ matching and carries out numerous other responsibilities relating to organ procurement and transplantation

### United Network for Organ Sharing (UNOS)

- Operates OPTN under contract with HRSA

### Scientific Registry of Transplant Recipients

- Provides statistical and other analytic support to OPTN for the formulation and evaluation of organ allocation

# Roles of State Entities in the Organ Donation and Transplantation System

Entity	Level	Role Within the Organ Donation and Transplantation System
<b>Agency for Health Care Administration</b>	State	Contracts with Donate Life Florida for online donor registration and education; coordinates with DHSMV to obtain donor registry funding; certifies and monitors organ procurement organizations for compliance and collects fees
<b>Donate Life Florida</b>	Private/ Nonprofit	Contracts with AHCA to operate a statewide online donor registry and provide donor education
<b>Department of Highway Safety and Motor Vehicles</b>	State	Coordinates with county tax collector offices; encourages and registers organ donors; provides donor educational materials; collects voluntary financial contributions to the donor registry
<b>County Tax Collector Offices</b>	Local	Encourage and register organ donors when issuing identification cards and driver licenses; may provide donor educational materials; collect voluntary financial contributions to the donor registry
<b>Organ Procurement Organizations (OPOs) (Certified by CMS)</b>	Regional Within the State	Follow policies set by CMS and OPTN; primarily responsible for procuring organs and matching donor organs to patients on waitlists and coordinating with hospital transplant centers for transport of matched organs
<b>Transplant Centers</b>	Local/Private/ Nonprofit	Evaluate patients to determine eligibility to be placed on waitlists and suitability of and procuring organs at donor hospitals after being contacted by an OPO; perform transplant surgeries and pre- and post-transplant care
<b>Donor Hospitals</b>	Local/ Private/ Nonprofit	Responsible for timely notification of OPO in their region of death or imminent death of a patient who is a viable organ donor

# Key Findings

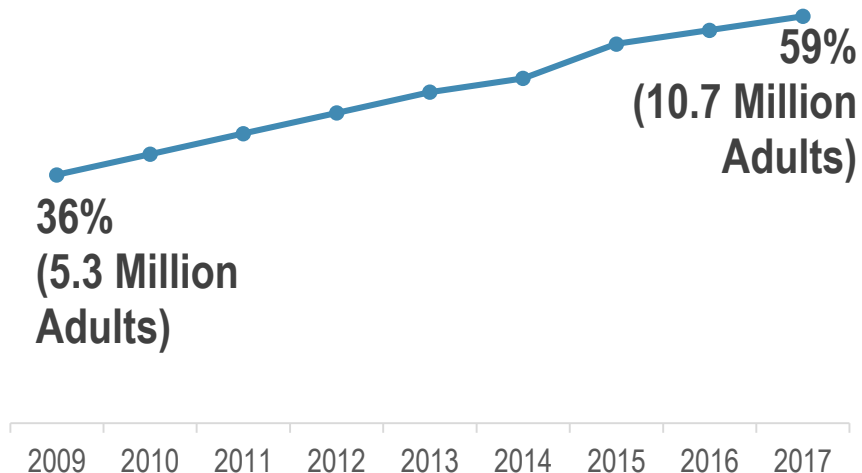
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- Florida's donor registration rate has increased over time and compares favorably to peer states, but there is room for improvement
- National organ allocation policy changes will negatively affect Florida's supply of kidneys and livers
- Factors contributing to transplant success include multidisciplinary teams and higher volume at transplant centers
- Stakeholder-identified challenges include misunderstanding or lack of support for organ donation and needing financial support for living donation
- AHCA's statutory fees exceed its costs; the excess could be used for donor education
- To increase organ availability, other states have passed legislation to support living donation and increase donor registration

# Florida's Donor Registration Rate Has Increased and Compares Favorably to Peer States






## Donor Registration Rate

Florida's donor registration rate has increased from 36% of adults 18 and older in 2009 to 59% in 2017



## Peer State Comparison

Florida performs better than its peer states in national rank for donor registrations

State	National Rank for Donor Registrations
 Florida	33
 Texas	41
 California	44
 Pennsylvania	45
 New York	50

# OPTN Policy Changes Affect Organ Allocation Nationally



In the past few years, OPTN has attempted to address a perceived equity issue in the allocation of organs

- Allocation was traditionally based on OPO donation service areas (DSAs) or OPTN regions

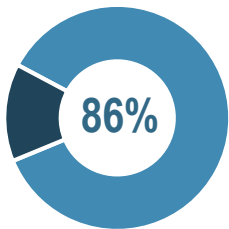


Since 2017, OPTN committees have made or adopted proposals to change organ allocation policies for lungs, livers, hearts, kidneys, and pancreases

- These policies change from allocating organs based on wait lists within DSAs or regions to allocating organs based on wait lists within nautical mile circles around donor hospitals (250 to 500 nautical miles, depending on the policy)
- The lung and heart policies have been implemented, while the kidney and pancreas policies are approved and awaiting implementation
- The liver allocation proposal was on hold due to a lawsuit, but based on a recent court decision, OPTN has announced it is moving forward

# UNOS Estimates That Policy Changes Will Negatively Affect Florida's Allocation of Kidneys and Livers

Organ	Annual Number of Transplants Pre-Change	Annual Number of Transplants Post-Change	Difference	Percentage Difference
Lung—Actual Volume over 1.5 Years	248	302	+54	+22%
—Projected Average	245	262	+17	+7%
Heart—Projected Average	273	294	+21	+8%
Kidney-Pancreas—Projected Average	46	64	+18	+39%
Liver—Projected Average	459	408	-51	-11%
Kidney—Projected Average	738	558	-180	-24%



As of June 2019, 4,706 people on Florida wait lists were waiting for a kidney, which represents the vast majority (86%) on wait lists

- An additional 9% were waiting for a liver



# Stakeholders and Research Studies Identified Several Factors Contributing to Post-Transplant Success

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## ■ Multidisciplinary teams

- Multidisciplinary teams bring together a variety of skills to treat patients pre- and post-transplant



## ■ Higher volume

- Several surgeons reported that higher volume is associated with better outcomes
- Many academic studies conclude that volume and patient outcomes are positively related but do not identify consistent minimum volume thresholds
- OPPAGA Report No. 19-11 recommended that the Legislature consider directing AHCA to create an advisory panel of transplant hospital representatives to examine clinical research and data and develop recommended volume thresholds



## ■ Other factors identified in academic research

- Include patient demographics and health characteristics or hospital and center-specific characteristics, such as staffing ratios and surgeon skill



## ■ Post-transplant care

- Access to needed medications, adhering to medication schedules, regular follow-up care, and maintaining a healthy lifestyle

# Stakeholders Identified Several Challenges to Florida's System

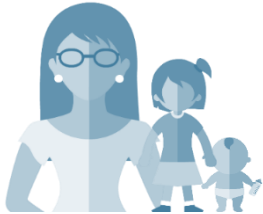
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Misunderstanding or lack of support for organ donation



Needing financial support to cover the costs incurred by living donors



Issues in hospital communication with families



Lack of consistent organ donation education in tax collector offices

# AHCA's Fees and Revenues are Designed to be Used for Multiple Purposes, Including Education

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AHCA collects fees from OPOs and tissue and eye banks

- Statutes require AHCA to use the fees to cover its regulatory costs for these entities, support the donor registry and donor education, and the costs of an advisory board that no longer meets



AHCA collected **\$670,039** in fees for FY 2018-19, but only spent **\$78,228** on regulating OPOs and tissue and eye banks



AHCA paid Donate Life Florida the revenues DHSMV and county tax collectors collected in voluntary contributions and left the excess revenues in its trust fund

- Donate Life Florida operates the state's donor registry and provides donor education under contract with AHCA

# States Have Passed Legislation to Address Living Organ Donation and Improve Registration

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## To improve organ availability through living organ donation

- Require certain employers to offer paid leave to living organ donors
- Offer tax credits or tax deductions to living donors or to employers who allow employees a leave of absence for living organ donation
- Prohibit insurance providers from denying coverage to living donors based solely on their status as living donors



## To improve donor registration

- Focus on education and public awareness of donor registration
- Expand the opportunities to register as an organ donor

# Legislative Options to Improve Organ Availability

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- Increase the rate of living organ donation
- Increase public support for organ donation
- Increase the number of registered donors

# Florida Legislative Options to Improve Organ Availability

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## ■ Education

- Increase public education about both living and deceased organ donation
- Add the topic of organ donation to continuing education requirements for health care professionals and to high school curriculum requirements (e.g., health science classes)



## ■ Employers

- Offer employers a corporate income tax or insurance premium tax credit for expenses incurred related to paying an employee or obtaining temporary assistance during the employee's leave of absence for living organ donation
- Require state and local government employers to offer paid leave for living organ donation

## ■ Coverage

- Allow Medicaid to cover medical expenses incurred by living organ donors
- Prohibit insurers from denying coverage to living organ donors based solely on their status as living donors



# Florida Legislative Options to Improve Organ Availability

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## ■ Funding

- Direct AHCA to use all excess revenues from fees paid by OPOs and tissue and eye banks for public education on donation



## ■ Registration

- Require county tax collectors to allow prominent display of organ donation educational materials in their offices
- Expand the opportunities to register as an organ donor to include additional points of access such as hunting and fishing licenses and state agency webpages

# Summary

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## Organ Allocation

National organ allocation policy changes will negatively affect Florida's supply of kidneys and livers; most people on Florida wait lists (86%) need kidneys



## Transplant Success

Post-transplant success can be enhanced by multidisciplinary teams and higher volume at transplant centers



## Barriers

Challenges stakeholders identified include misunderstanding or lack of support for organ donation and living donors needing financial support to cover their costs



## Other States

To increase organ availability, other states have implemented legislation to support living organ donation and increase donor registration



# Summary of Legislative Options for Consideration

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## ■ Education

- Increase public education about both living and deceased organ donation
- Add the topic of organ donation to education requirements for health care professionals and to high school curriculum requirements



## ■ Employers

- Offer employers tax credits for expenses related to employees acting as living donors
- Require state and local government employers to offer paid leave for living organ donation



## ■ Coverage

- Allow Medicaid to cover living donor medical expenses
- Prohibit insurers from denying coverage to living organ donors



## ■ Funding

- Direct AHCA to use all excess revenues from fees paid by OPOs and tissue and eye banks for public education on donation



## ■ Registration

- Require county tax collectors to allow prominent display of organ donation educational materials in their offices
- Expand the opportunities to register as an organ donor to include additional points of access such as hunting and fishing licenses and state agency webpages

# Contact Information

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FLORIDA LEGISLATURE OFFICE OF PROGRAM POLICY ANALYSIS AND  
GOVERNMENT ACCOUNTABILITY

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OPPAGA supports the Florida Legislature by providing data, evaluative research, and objective analyses that assist legislative budget and policy deliberations.