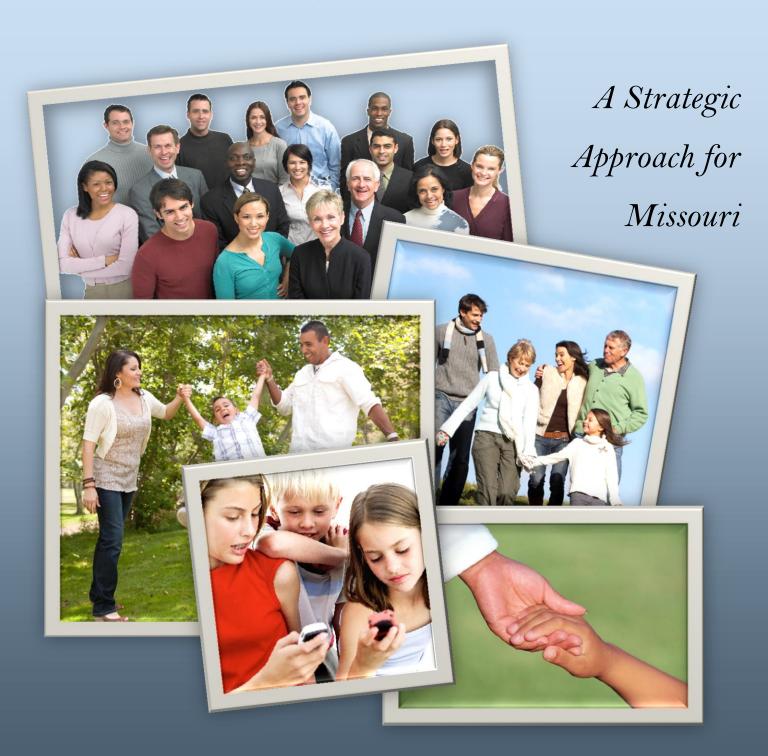
Saving and Enhancing Lives

Through Organ, Eye and Tissue Donation -



FY16 Status Report



The FY16 Status Report is a public document and may be copied and shared for the purposes of informing, educating, promoting, and coordinating efforts to increase awareness about organ, eye and tissue donation and increase donor designations recorded in the Missouri Donor Registry System.

Missouri Department of Health and Senior Services Division of Community and Public Health; Bureau of Cancer and Chronic Disease Control

Missouri Organ and Tissue Donor Program
920 Wildwood Drive, PO Box 570, Jefferson City, Mo. 65102-0570
P: 573.522.2847 or 888.497.4564 F: 573.522.2898
www.health.mo.gov/organdonor

AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER Services provided on a nondiscriminatory basis.

· Missouri Department of Health and Senior Services · Governors Organ Donation Advisory Committee ·

A Public Health Issue

Organ donation remains a public health issue despite advancing medical technology, treatment options and the rise in the number of registered potential donors. Every 10 minutes someone is added to the national transplant waiting list and on average 22 people die daily while waiting for a life-saving transplant. Nationwide the organ transplant waiting list continues to grow; 118,557 people and of those, 76,035 people are active waiting list candidates. The Department of Health and Senior Services (DHSS) and its partners use these and other statistics to monitor need and to drive educational efforts. Data also assists in planning and evaluation efforts.

This report contains a snapshot of national and Missouri data. Through the United Network of Organ Sharing's (UNOS) Organ Procurement and Transplant Network (OPTN) website additional data sets can be accessed. Also included are the strategic plan priority areas, followed by summary pages of the current goals, objectives and progress status. Partner and stakeholder information, when submitted, is included as part of this status report. The current strategic plan is available at www.health.mo.gov/living/organdonor/publications.

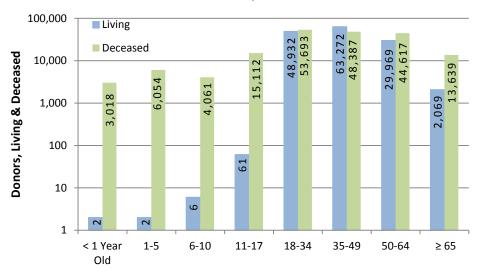
National Data

Data subject to change based on future data submission or correction. Source: Organ Procurement and Transplant Network (https://optn.transplant.hrsa.gov/)

People of every age give and receive organ donations.

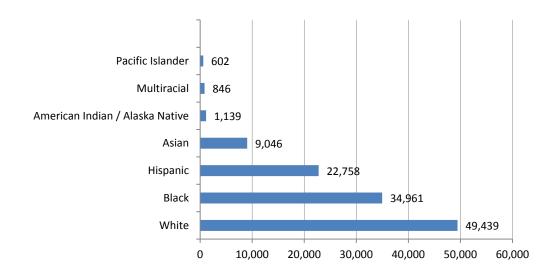
U.S. Organ Donors by Donor Type by Age

Jan 1998 - Sept 2016

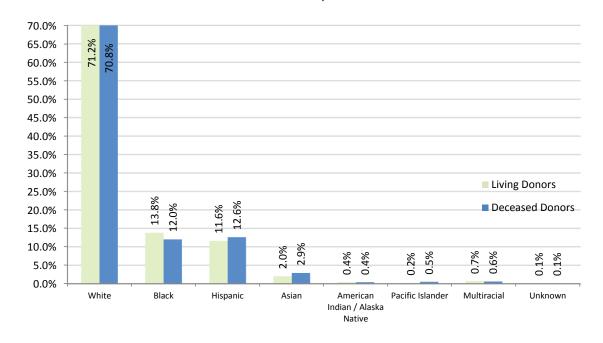


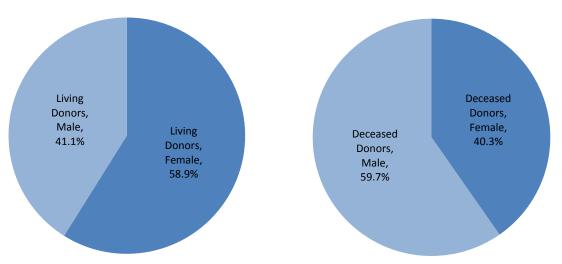
U.S. Waitlist by Race/Ethnicity

Based on OPTN data as of February 20, 2017



U.S. Donors Jan 1988 - Sept 2016





Missouri Data

2,700,000

FY12

Data subject to change based on future data submission or correction. Data sources: Source: Organ Procurement and Transplant Network (https://optn.transplant.hrsa.gov/) and Missouri Donor Registry System.

Donor designation rate is the rate at which individuals' join the state donor registry as a percentage of all driver's licenses and identification cards issued within a specific time. There continues to be an increase in donor designations recorded in the Donor Registry System (DRS). At the close of fiscal year 2016, 3,532,646 individuals designated themselves as potential donors. The number of registrants in Missouri's Donor Registry System continues to rise gradually. While the average increase each year has slowed, the number of registrants has increased by 17.6 percent since FY12. The slowing of yearly registrations may be due to a six-year driver license renewal cycle for most residents issued/renewed on an individuals' day of birth. Other contributing factors may be the "53" and Donate Life America's "Register Me" registries. Both launched in FY16. The fluctuation in driver's license transactions can range from 115,600 to 153,000 a month. At the close of the 2015 calendar year, Missouri's donor designation rate at local license offices was 47%.

3,600,000 3,500,000 3,400,000 3,200,000 3,100,000 3,000,000 2,900,000 2,800,000

Missouri Residents Registerd as Organ, Eye and Tissue Donors

Missouri's population demographic breakdown; Whites 84.6 percent, Blacks 12.5 percent and Other 2.9 percent. The actual number of available and viable donors at the time of death compared to the number of individuals on the waiting list for an organ creates the gap between need and availability. Every person is a potential donor. Viability assessment is determined at or near time of death. Missouri statistics follow.

FY14

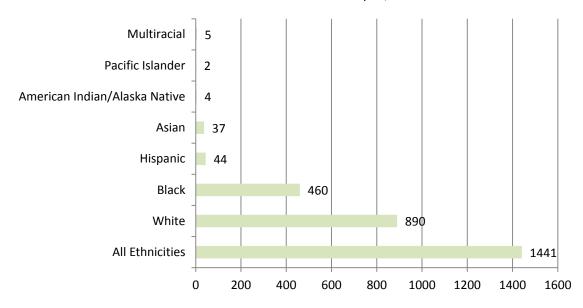
FY15

FY16

FY13

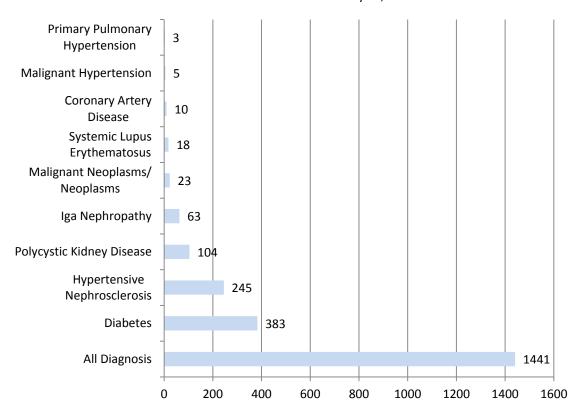
Mo. Waitlist: Candidates by Race/Ethnicity

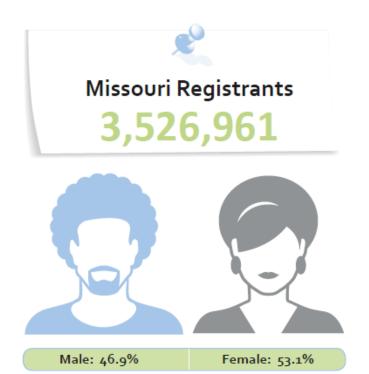
Based on OPTN data as of Febraury 20, 2017



Mo. Waitlist: Candidates by Diagnosis

Based on OPTN data as of February 20, 2017





Registered by Age Census Table

Age Group	Registrants 7/2/2016	2015 Census Est.	Percent of State Population Registered
<=14	10,771	1,151,685	0.94%
15-17	180,568	239,791	75.30%
18-24	672,963	587,399	114.57%
25-34	711,464	806,767	88.19%
35-44		732,675	81.34%
45-54	569,016	805,291	70.66%
55-64	452,342	805,142	56.18%
>=65	333,884	954,922	34.96%
Total Registrants	3,526,961		
Total Population Est. 6,083,672			
Total Percent of State	e Population Reg	istered	57.97%

Registered by Age Distribution

65+	333,884
55-64	452,342
45-54	569,016
35-44	595,953
25-34	711,464
18-24	672,963
15-17	180,568
<14	10,771

Source: Missouri Donor Registry System



Data subject to change based on future data submission or correction. Source: Missouri Organ and Tissue Donation 2016 Annual Report (http://health.mo.gov/living/organdonor/publications.php)

MISSOURI SNAPSHOT



2,317

Number of registrants ever waiting by age group at time of listing where the candidate's home state is Missouri. Total number of patients over all age groups is less than the sum of patients due to multiple listings and multiple timing of listings.

By Age and Percentage

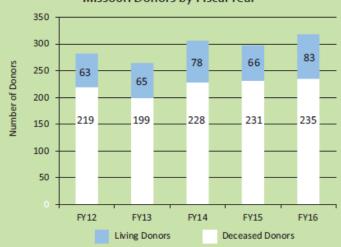
18.5%
43.9%
24.1%
12.5%
1.9%
0.4%
1.8%

Missouri Registrants Ever Waiting by Age by Fiscal Year

	FY12	FY13	FY14	FY15	FY16
<1	22	11	11	13	17
1-5	19	18	17	19	24
6-10	18	15	15	11	10
11-17	29	35	35	43	44
18-34	281	282	274	312	289
35-49	608	629	588	557	558
50-64	979	1,045	1,067	1,028	1,017
65+	354	406	398	411	429
Total	2,310	2,443	2,328	2,327	2,317

Note: Number of registrants ever on wait list for a transplant by age, by fiscal year where the candidate's home state is Missouri. Candidate age is at the time of listing. Registrations may be counted in different time periods.

Missouri Donors by Fiscal Year



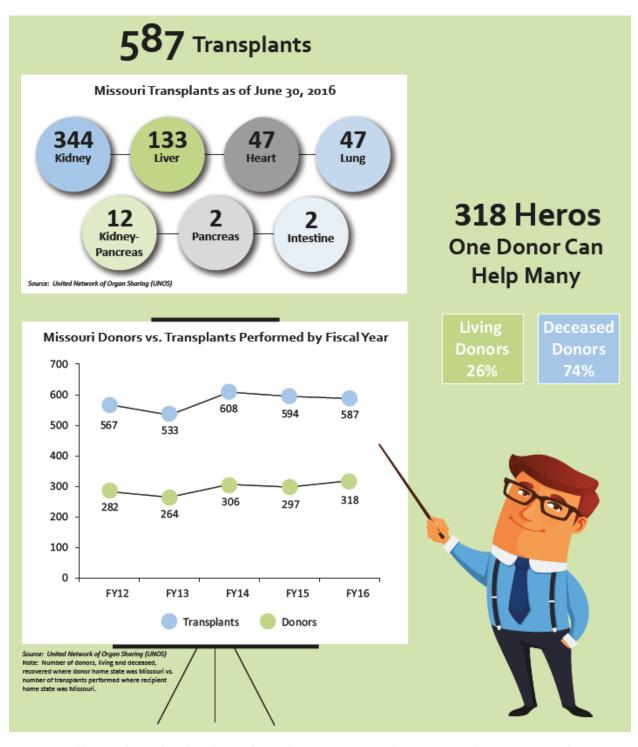
Source: United Network of Organ Sharing (UNOS)

Recovery Authorized by the Registry

	FY14	FY15	FY16
Organ Donors	128/52.5%	127/46.9%	133/55.6%
Tissue Donors	817/59.0%	843/59.8%	762/59.4%
Eye/Comea Donors	1,002/53.4%	1,418/58.4%	899/55.4%

Source: Missouri organ and tissue procurement agencies

Data subject to change based on future data submission or correction. Source: Missouri Organ and Tissue Donation 2016 Annual Report (http://health.mo.gov/living/organdonor/publications.php)



Data subject to change based on future data submission or correction. Source: Missouri Organ and Tissue Donation 2016 Annual Report (http://health.mo.gov/living/organdonor/publications.php)

Several factors contribute to Missouri's increase in registered donors and the donation gap: transplantation as a successful treatment option; the aging population; increased life expectancy; medical breakthroughs; high percent of individuals with diabetes, high blood pressure or both; and educational efforts provided by partners, local and national.

Strategic Plan Priority Areas

The plan has five primary priority areas: education, data, finance, registry, and stakeholders. A brief statement accompanies each below and the heading links to the goals and objectives for that priority area.

Education

Utilizing social media, providing positive publicity, expanding partnerships, bridging efforts and educating people of all ages are opportunities to explore. The plan addresses education in a variety of settings and target populations.

Data

Assessing current conditions, evaluating activities and measuring progress toward goals and objectives are possible with data. In addition, data helps direct educational efforts. Monitoring data needs and capacity, enhancing data availability and sharing data are opportunities to aid decision making. The plan addresses data accuracy and relevancy.

Finance

Partners encourage contributions to the Organ Donor Program Fund. The fund supports education and registry maintenance and modification. Plan goals address financial sustainability and transparency.

Registry

Ever changing technology and public demands of that technology are indicators of how people learn, communicate and process information. Constant monitoring, maintenance and upgrades to the Donor Registry System (DRS) are necessary to remain current. The plan addresses technology while maintaining confidentiality.

Stakeholders

As technology and health care systems continually change, medical breakthroughs are made and cultural beliefs change, it is critical that groups with similar goals and complimentary services, work together to maximize resources and reach. Through effective partnerships, educational opportunities expand and residents become better informed. Communication, engagement and clearly defined roles provide opportunities to develop new partnerships while advancing existing partnerships to enhance education efforts. The plan addresses stakeholder engagement.

Priority Area	Data – Data that Informs		
Goal:	Accurate and relevant data used to make informed decisions.		
Objective(s):	1. By June 2018, upgrade Donor Registry System reporting features to provide timely data without compromising confidentiality.		
Status: Behind	6/30/15: Request with information technology group		
Schedule	6/30/16: Request with information technology group. DHSS program staff researching Donor Registry System Options		
Progress Notes:			
Priority Area	Education – Emergency Management Services (EMS)		
Goal:	Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.		
Objective(s):	 By June 2017, increase from zero to 500 the number of emergency management personnel that complete the <i>Keep Hope Alive</i> training. By June 2017, increase knowledge among emergency management personnel as measured by <i>Keep Hope Alive</i> training pre- and potest scores. By June 2018, increase from zero to 12 the number of <i>Keep Hope Alive</i> presentations to fire and/or Emergency Management Services. 		
	departments. Avg. Pre-Test Avg. Post-		
	Fiscal year Score Test Score		
	FY 14 67.8 % 82.8%		
	FY15 80.4% 88.3%		
	FY16 83.7% 95.7%		
	6/30/14		
Status: On Target	 Permissions received from Sierra Donor Services and Department of Health and Senior Services' Bureau of Emergency Medical Services. Pre- and post-tests developed and approved. CEU's secured from University of Missouri. Introduction script written, approved and recorded. Moderator secured (<i>Deb Simaitis, donor mother</i>). Recording and editing of scripts completed. Training development completed (combining components). Two formal presentations given. 6/30/15 Emergency Medical Technicians (EMTs) in Boone county are routinely encouraged to take the course by the University of Missouri (ongoing). 		

• GODAC committee chair contacted CECEMSW and NREMT and discussions are ongoing.

6/30/16

• Midwest Transplant Network designed and implemented a training for EMTs in their service area (does not include KHA video).

- Between December 2013 through June 2016, 134 emergency personnel (emergency medical technicians, paramedics, first responders, and volunteer firefighters) completed the training. This figures does not include training provided by Midwest Transplant Network as no data submission as the time this report was published.
- Article written by DHSS and published in Missouri EMS Connection (Spring 2016 issue).
- Staff change at NREMT has slowed progress.
- NREMT suggested contacting the education department of the National Association of Emergency Medical Technicians (NAEMT).

	This action will be added to the next revision of the strategic plan.		
Priority Area	Education – Local Driver License Offices		
Goal:	Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.		
Objective(s):	 By June 2018, develop and deploy a training program for all local license office employees about organ, eye and tissue donation a the donor registry system. 		
	Number of registry enrollments among individuals 18 years of age and older		
	6/28/2014 3,096,109		
	6/27/2015 3,207,558		
	7/02/2016 3,335,622		
	6/30/16		
Status: On Target	 Mid-America Transplant developed training and trained three offices for which they held the contract. Review objective and action steps during FY17/18. 		
, and the second	 89 local license offices in Midwest Transplant Network's service area received the monthly educational newsletter developed and published by their agency. 		
	 89 local license offices in MTN's service area also received the "Licensed for Life" quarterly educational newsletter developed and published by their agency. 		

• 179 offices statewide received a copy of the Annual Report. **Priority Area Education – High School Education**

Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.

information relevant to the local license offices about organ, eye and tissue donation.

1. By June 2016, increase the number of high schools implementing the Gift of Life program from 80 as of June 30, 2013 to 90.

2. By June 2018, offer a minimum of two organ and tissue donation learning module options for public schools.

Note: 18 year olds are considered adults and not counted in the following data. Measure needs to be modified to reflect current data reports available in the DRS (15-17 year olds) in the next revision to the strategic plan.

179 offices statewide receive a quarterly newsletter from the Department of Health and Senior Services. The newsletter contains

Number of registry enrollments among individuals 18 years of age and older

6/28/2014 171,252 6/27/2015 174,285 7/2/2016 180,568

6/30/16

Goal:

Objective(s):

Status: On Target

• Work team identified and Gift of Life (KC) representative is the team lead. Team representation: GODAC, DESE, GOL, Missouri

Kidney Program, Mid-America Transplant and DHSS.

- Based on the success of the LifeSavers[™] program, team moving forward to expand it rather than evaluating other programs at this time. As of November 2015, 90 high schools have implemented the program.
- High School Education Program Accomplishments:
 - IRB Waiver received.
 - Teacher Survey and student focus group questions developed.
 - Student focus group questions developed.
 - Two pilot student focus groups completed to test questions.
 - Presentations made at Project Lead the Way and the East and West Fall HOSA Leadership Conferences. Highlighted
 expanding the program, encouraged participation in the student focus groups and asked teachers and sponsors to complete
 the teacher survey by November 15, 2016.
 - Student focus groups planned for the spring 2017 HOSA conference.
 - o Teacher survey executed, data collected and data shared with the work group.
 - o Organ donation information session at state HOSA conference (March 2016).
 - o Currently the LifeSavers program is in eight Missouri counties: Adair, Benton, Cass, Jackson, Platte, Clay, Lafayette and Ray.
- Action step(s) dates to be modified by the workgroup and published in the next time revisions of the plan.
- Objectives to be reviewed in FY 2017.

Priority Area

Education – Adults 50 years of age and older

Goal:

Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.

Objective(s):

1. By June 2018, adopt or develop and distribute materials dedicated to myths about age, cancer and medical care among the state's adult population 50 years of age and older.

6/30/15

- Phil Duncan, GODAC member and volunteer, traveled with the Donate Life Globe in several community holiday and event parades, state capitol and the Missouri State Fair.
- DHSS aired radio PSA developed by HRSA (April 2015). Outcome published in the FY15 annual report on the publications page of www.health.mo.gov/organdonor.
- Team Missouri developed a communication plan for the team.

6/30/16

Status: On Target

- Phil Duncan, GODAC member and volunteer, traveled with the Donate Life Globe in several community holiday and event parades, state capitol and the Missouri State Fair.
- Team Missouri chose this goal and objective as a priority area as it relates to social media. Team leader was Michala Stoker, Saving Sight. Co-leader was T'Shon Young, Mid-America Transplant. Team is made up of staff from Mid-America Transplant, Midwest Transplant and Saving Sight. No report at time of publication.
- DHSS repeated the radio PSA during April and May 2016. While all age groups increased in registration, the increase was not statistically significant. Details available in the FY16 Annual Report posted on the publications page of www.health.mo.gov/organdonor.
- "8 Truths" poster being designed for distribution to local license offices and public libraries.

Priority Area	Education – Social Media		
Goal:	Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.		
Objective(s):	1. By June 2018, distribute organ and tissue donation information through Twitter, Facebook, YouTube and the Internet.		
Status: On Target	 6/30/16 Team Missouri reported their focus was on messages for the Donate Life Missouri Facebook page. Team leader will work with GODAC member, Peter Nicastro, to update the GODAC Dashboard with new measures. DHSS continues to review and update website information related to organ, eye and tissue donation (www.health.mo.gov/organdonor). Midwest Transplant Network reported 509 Facebook posts to their web page, 127 Tweets and seven new YouTube videos. Midwest Transplant Network reported 8,133 Facebook likes and 1,005 Twitter followers and 3,927 You Tube views. 		
Priority Area	Education – Faith-based Opportunities		
Goal:	Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.		
Objective(s):	1. By June 2018, engage at least one religious leadership organization in organ, eye and tissue donation and Registry education efforts.		
Status: On Target	 6/30/16 Team lead, Joan Keiser, identified in January 2016. DHSS released an invitation for bid. Mid-America Transplant applied and received an award: Nine churches received program. 338 participants and their families reached. Mid-America Transplant's award was extended through FY17. 6/30/17 Team lead identified three Springfield, Mo. UMC churches. 		
Priority Area	Education – Living and Other Donation Types		
Goal:	Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.		
Objective(s):	1. By June 2018, inform public about living and other donation types.		
Status: On Target	Note: Annual reports are available at http://www.health.mo.gov/living/organdonor/publications.php . Report information includes submissions from partners including Midwest Transplant Network, Mid-America Transplant, Saving Sight, Gift of Life and Missouri Kidney Program 6/30/2014 • Living Kidney Donor Story and data included in the annual report. 6/30/2015 • Living Liver Donor Story and data included in the annual report. 6/30/2016 • Living donor data included in the annual report.		

Priority Area	Finance – Sustainability		
Goal:	Sustainable funding supports Donor Registry System operation and educational programs.		
Objective(s):	 By close of 2017 legislative session, reauthorize the Missouri Income Tax check off. By June 2018, ensure a continual fund balance of three years of operating expenses. By June 2018, establish an online contribution mechanism for the Organ Donor Program Fund. 		
Status: On Target	 Note: Annual reports are available at http://www.health.mo.gov/living/organdonor/publications.php. 6/30/2014 Organ Donor Program Fund report published in the Annual Report. 6/30/2015 Organ Donor Program Fund report published in the Annual Report. 6/30/2016 While determined the process to reauthorize or extend the sunset date in Statute 143.1016, Senator Parson informed the GODAC Chair, Deb Simaitis, that his office formed a legal team to write a bill for his sponsorship. Representative Love will be sponsoring the house bill (HB 1673). Both bills were submitted with the same language and considered a consent bill. SB 738 pre-filed on December 1, 2015. Organ Donor Program Fund report published in the Annual Report. Sunset Clause Repeal of the Income Tax Checkoff did not pass. 		
Priority Area	Finance – Stewardship		
Goal:	Transparent stewardship of the Organ Donor Program Fund.		
Objective(s):	1. By June 2018, provide budget reports to advisory committee, partners and the public.		
Status: On Target	 Note: Annual reports are available at http://www.health.mo.gov/living/organdonor/publications.php. 6/30/2014 Quarterly reports to the Governor's Organ Donation Advisory Committee completed and included income, expenses and variance. Annual budget report posted in the annual report. 6/30/2015 Quarterly reports to the Governor's Organ Donation Advisory Committee completed and included income, expenses and variance. Annual budget report posted in the annual report. 6/30/2016 Quarterly reports to the Governor's Organ Donation Advisory Committee completed and included income, expenses and variance. Annual budget report posted in the annual report. 		

Priority Area	Registry – Functionality	
Goal:	A confidential and technologically current Donor Registry System.	
Objective(s):	 By December 2017, Donor Registry System will be mobile friendly. By June 2018, streamline the registration process of the Donor Registry System. 	
	 6/30/2013 Donor Registry System Mobile Enrollment Component survey conducted to determine usage and viability. 6/30/2014 Donor Registry System Maintenance Customer Service Request (CSR) completed and reviewed with Office of Administration 	
	 Information Technology Services Division (ITSD) representative. Donor Registry System Report Survey of users to determine usage, satisfaction and future reporting needs. CSR drafted and began review process for reporting feature updates to be submitted to ITSD. 6/30/2015 	
	 CSR for confirmation letter updates submitted through the established DHSS Division of Community and Public Health (DCPH) process to ITSD. Request completed. CSR for reporting feature updates submitted through the established DHSS DCPH process to ITSD. 	
Status: Behind Schedule	 CSR for intent records, profile and processes modification requested submitted through the established DHSS DCPH process to ITSD. CSR for reporting feature updates re-submitted and included Spanish language updates to online enrollment process through the established DHSS DCPH process to ITSD. 	
	 CSR for name and logo changes of partners as well as removal of contractor users submitted through the established DHSS DCP process to ITSD. CSR for enhancements and efficiencies to the Donor Registry System drafted (later incorporated into the consolidated CSR. CSR detailing application modifications, enhancements and documentation submitted to ITSD. Submission information combined submissions from previous years and then sorted by priority per the Department's ITSD liaison. 6/30/2016 	
	 Suggested improvements submitted by Midwest Transplant Network. National Registry System information gathering conducted by Organ and Tissue Donor Program. Other state registry information gathering conducted by Organ and Tissue Donor Program staff. Proposals written and submitted to DHSS management for alternatives to the existing Missouri Donor Registry System. 	
Priority Area	Stakeholders – Communication	
Goal:	Engaged stakeholders making recommendations for Donor Registry System operations and education initiatives through open and transparent communication.	
Objective(s):	 By June 20, 2015, document roles of primary stakeholders. By June 30, 2015, document communication process between the advisory committee and the Department. By June 30, 2015, publish the role of the Donate Life Missouri team. 	

4. By June 2018, engage stakeholders on Donor Registry System operations and education efforts.

6/30/2013

- Roles documented for GODAC, OPOs, GOL and Team Missouri.
- Advisory committee meetings/conference calls held:
 - o September 6, 2012
 - o November 30, 2012
 - February 19, 2013
 - o April 4, 2013
 - o May 23, 2013

6/30/2014

- Committee utilizes the SBAR (Situation, Background, Assessment and Recommendation/Requests) format to communicate with the DHSS.
- Committee and partners helped develop and implement the statewide strategic plan prior to publishing.
- Advisory committee meetings/conference calls held:
 - o July 25, 2013.
 - September 27, 2013.
 - o December 23, 2013.
 - o February 21, 2014.
 - o May 9, 2014.

6/30/2015

- GODAC online training developed and released.
- GODAC members required to take the training annually.
- All members completed training.
- All members signed confidentiality agreements.
- A citizen group formed and working to draft statute updates:
 - o Language updated to current terminology.
 - o DESE representative added to the advisory committee.
 - Other entities eligible for grant funding.
- Committee and partners report and review strategic plan status report prior to publishing on the web.
- Committee and partners review and revise strategic plan prior to publishing on the web.
- Advisory committee meetings/conference calls held:
 - o July 17, 2014.
 - o September 25, 2014.
 - o December 9, 2014.
 - o March 6, 2015.
 - o May 28, 2015.

Status: On Target

6/30/2016

- Most GODAC members completed annual training.
- Citizen group has temporarily suspended drafting statute changes until the tax sunset clause removal received approval (Statute 143.1016).
- Committee and partners report and review strategic plan status report prior to publishing on the web.
- Committee and partners review and revise strategic plan prior to publishing on the web.
- Advisory committee meetings/conference calls held:
 - o July 22, 2015.
 - September 23, 2015.
 - o December 10, 2015.
 - o March 4, 2016.
 - o June 8, 2016.

UNOS: This work was supported in part by Health Resources and Services Administration contract 234-2005-37011C. The content is the responsibility of the authors alone and does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government.

ⁱ Organ Procurement and Transplantation Network (OPTN). February 8, 2016. Retrieved from <u>http://www.unos.org/data/</u>

[&]quot;Organ Procurement and Transplantation Network (OPTN). (September 30, 2016). Data Reports and Policies. Retrieved from http://optn.transplant.hrsa.gov/converge/latestData/advancedData.asp

iii Missouri Department of Revenue. (April 2013). Driver/Identification Transactions for Calendar Years 2010, 2011, and 2012

^{iv} Donate Life America 2016 Annual Update

V Department of Health and Senior Services. (January 28, 2015). Population MICA. Retrieved from health.mo.gov/data/mica/population.php, November 14, 2016

vi Department of Health and Senior Services, 2016 Annual Report Missouri Organ and Tissue Donation. Retrieved from http://health.mo.gov/living/organdonor/publications.php, January 15, 2016