

Saving and Enhancing Lives

Through Organ, Eye and Tissue Donation –

*A Strategic
Approach for
Missouri*



FY18 Status Report

12/1/2018



The FY18 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

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

• Missouri Department of Health and Senior Services • Governor's 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. Someone is added to the national transplant waiting list every 10 minutes. On average 20 people die daily while waiting for a life-saving transplant. Nationwide the organ transplant waiting list continues to grow; 116,109 people and of those, 75,443 people are active waiting list candidates.¹ 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. Additional data sets are available through the United Network for Organ Sharing's (UNOS) Organ Procurement and Transplant Network (OPTN) website. 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.php.

Organ Donation Statistics At-A-Glance

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.ⁱⁱ

National Statistics:

Source: <https://www.organdonor.gov/statistics-stories/statistics.html> pulled August 20, 2018.

114,000+

number of men, women and children on the national transplant waiting list as of April 2018.

34,770

transplants performed in 2017.

20

people die each day waiting for a transplant.

95%

of U.S. adults support organ donation.

BUT ONLY

54%

are actually signed up as donors.

every 10 minutes

another person is added to the waiting list.

only 3 in 1,000

people die in a way that allows for organ donation.

The organ shortage continues. Each year, the number of people on the waiting list continues to be much larger than both the number of donors and transplants, which grow slowly.ⁱⁱⁱ

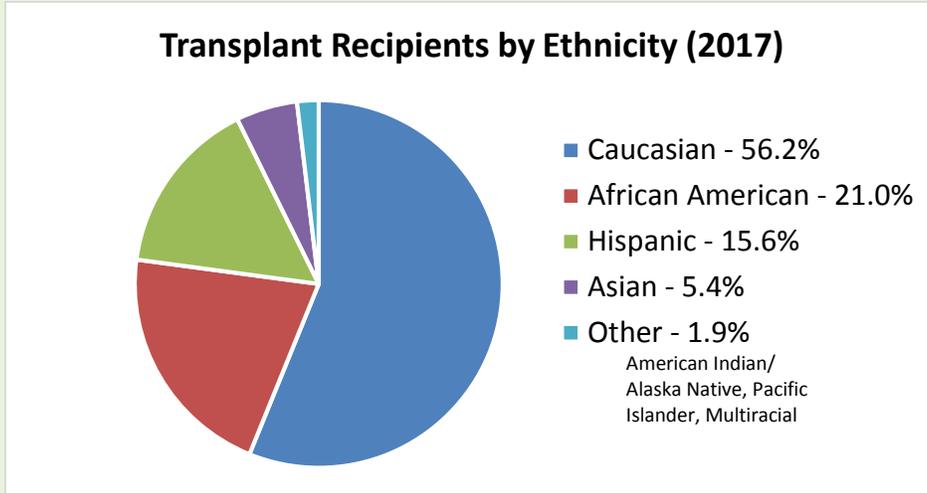
As of April 2018, there are more than 114,000 candidates for transplant on the U.S. national waiting list according to U.S. Department of Health & Human Services.

- Two out of every three people on the waiting list are over the age of 50.
- Almost 2,000 children under 18 are on the waiting list.
- Almost 70,000 people (58 percent) on the list are ethnic minorities.
- People are waiting for the following organs. Total is more than 100 percent due to patients included in multiple categories.
 - Kidney – 83.0%
 - Liver – 12.1%
 - Heart – 3.5%
 - Lung – 1.2%
 - Other – 2.5% (pancreas, intestines and combinations)

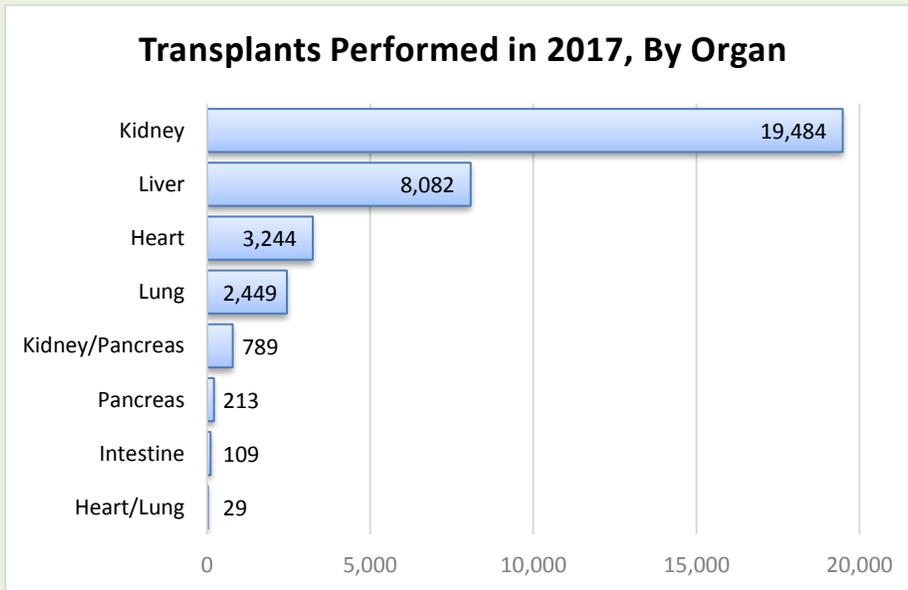
View current data by age, ethnicity, health status, gender, average waiting times, candidates vs. registrants, and more at OPTN Data Reports (<https://optn.transplant.hrsa.gov/>).

Transplants performed in 2017 was a new record high for the fifth consecutive year, 34,770 transplants.

- Each day, about 80 people receive organ transplants. Of these recipients, the breakdown of ethnic backgrounds includes:



- In 2017, about 62 percent of organ recipients were male; 38 percent female.
- More than 84,000 corneal transplants performed in 2017.
- More than 1 million tissue transplants performed each year.



Visit [OPTN Data Reports \(https://optn.transplant.hrsa.gov/\)](https://optn.transplant.hrsa.gov/) for current data on transplants performed, including by recipient age, ethnicity, gender, or state.

42,609

Donated Organs

6,181

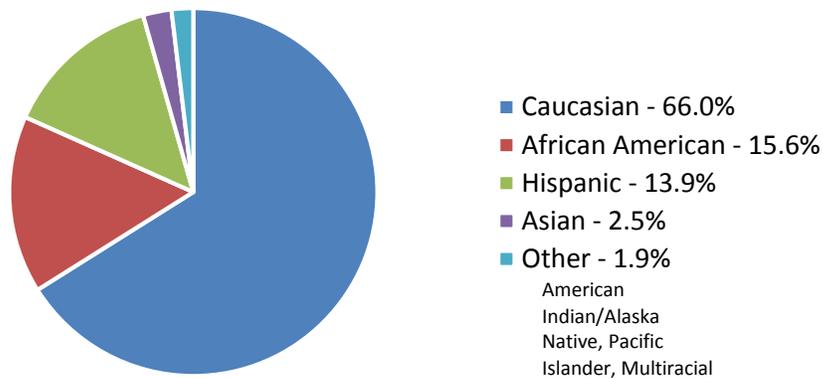
Living

36,407

Deceased

- More than four out of five donations come from deceased donors, and one out of five from living donors.
- Nearly six in 10 donors are deceased and about four out of 10 are living donors.
- Thirty-four percent of deceased donors in 2017 were over the age of 50.
- Sixty percent of deceased donors in 2017 were male, 40 percent female.

Deceased Donors by Ethnicity (2017)



For current statistics about deceased and living donors, including age, race/ethnicity, gender, state and more, visit the [OPTN Data Reports \(https://optn.transplant.hrsa.gov/\)](https://optn.transplant.hrsa.gov/) for current statistics.

138,000,000+

More than 138 million people over the age of 18 registered as organ donors in 2015, more than half of all U.S. adults.

(Source: DLA Donor Designation Report update released 3/31/16)

Missouri Statistics:

Data subject to change based on future data submission or correction. Data sources: Organ Procurement and Transplant Network (<https://optn.transplant.hrsa.gov/>) and Missouri Donor Registry System. Missouri statistics are based on fiscal year (FY) 18 (July 1, 2017 through June 30, 2018) unless specified.

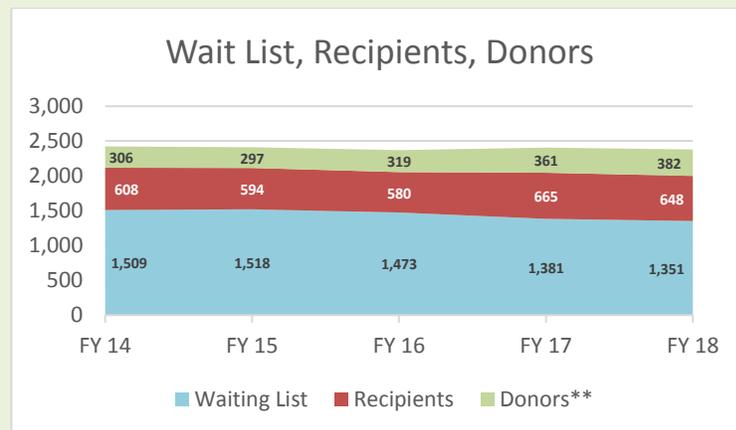
The actual number of available and viable donors at the time of death compared to the number of individuals on the waiting list for an organ creates the gap between need and availability. Several factors contribute to Missouri's increase in registered donors and the donation gap: educational efforts provided by local and national partners; transplantation as a successful treatment option; the aging population; increased life expectancy; medical breakthroughs; and high percent of individuals with diabetes, high blood pressure, or both. Every person is a potential donor. Viability assessment is determined at or near time of death. Missouri statistics follow.

1,300+

Gap

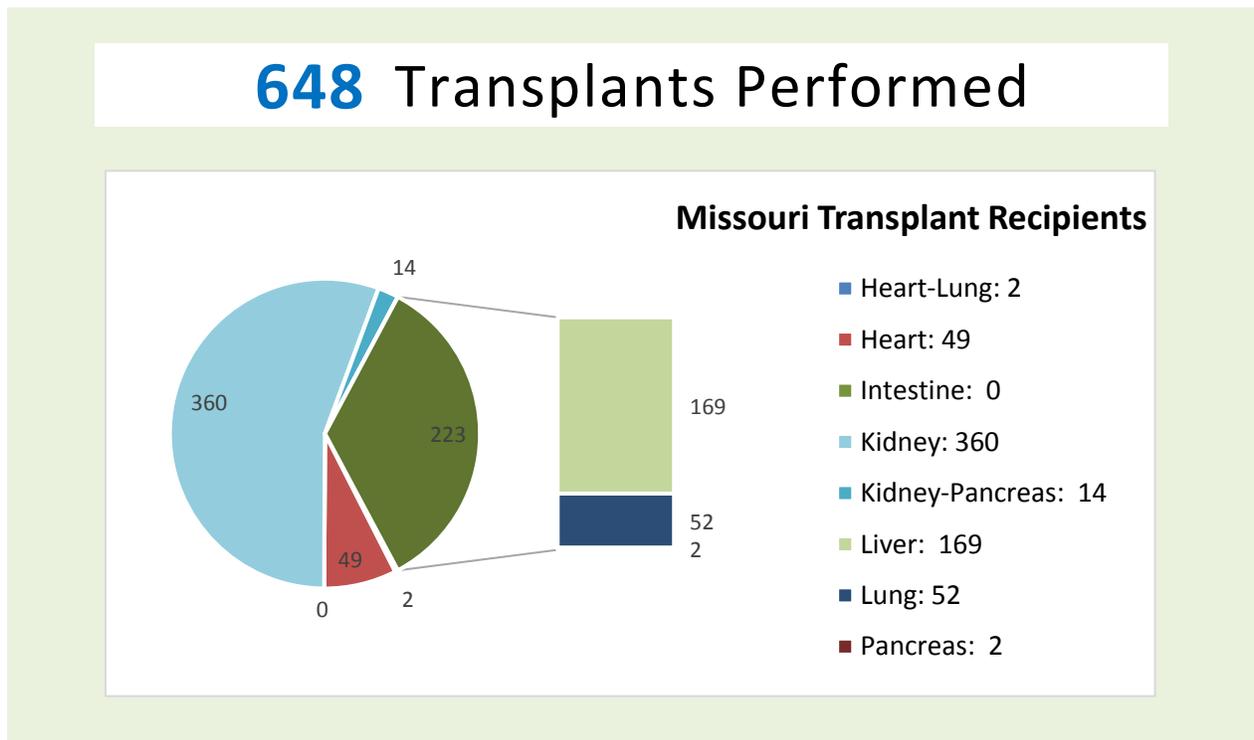
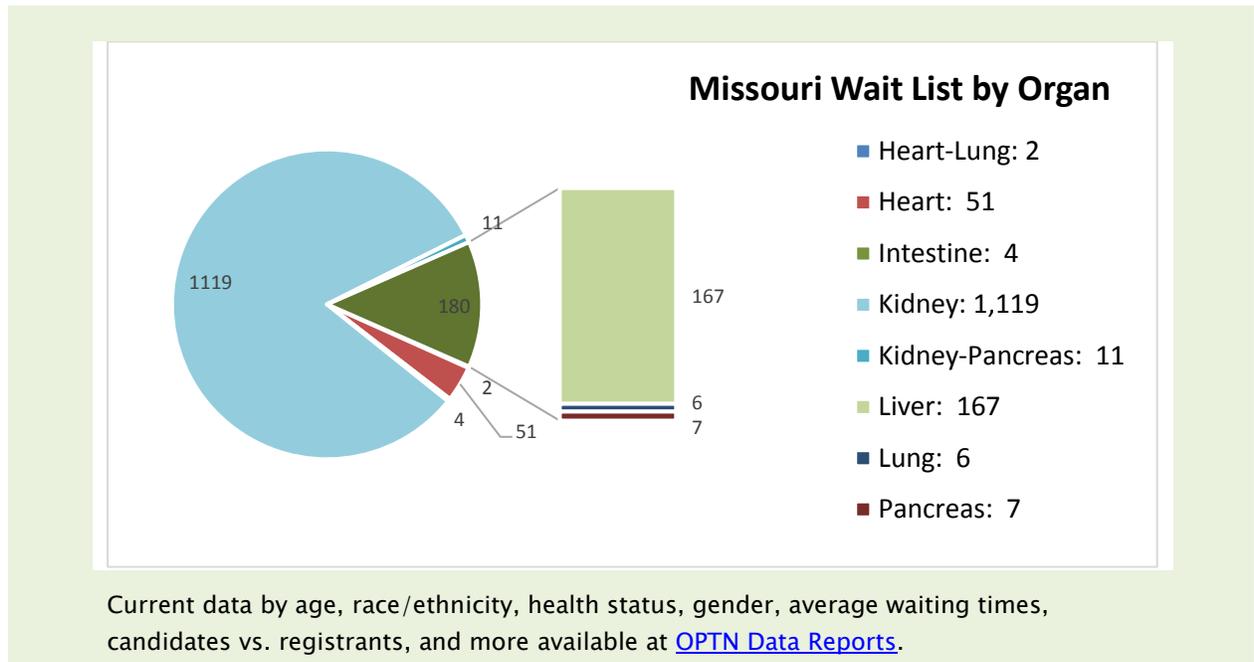
The gap between the number of people on the waiting list continues and is larger than the number of donors and transplants, which continue to grow.

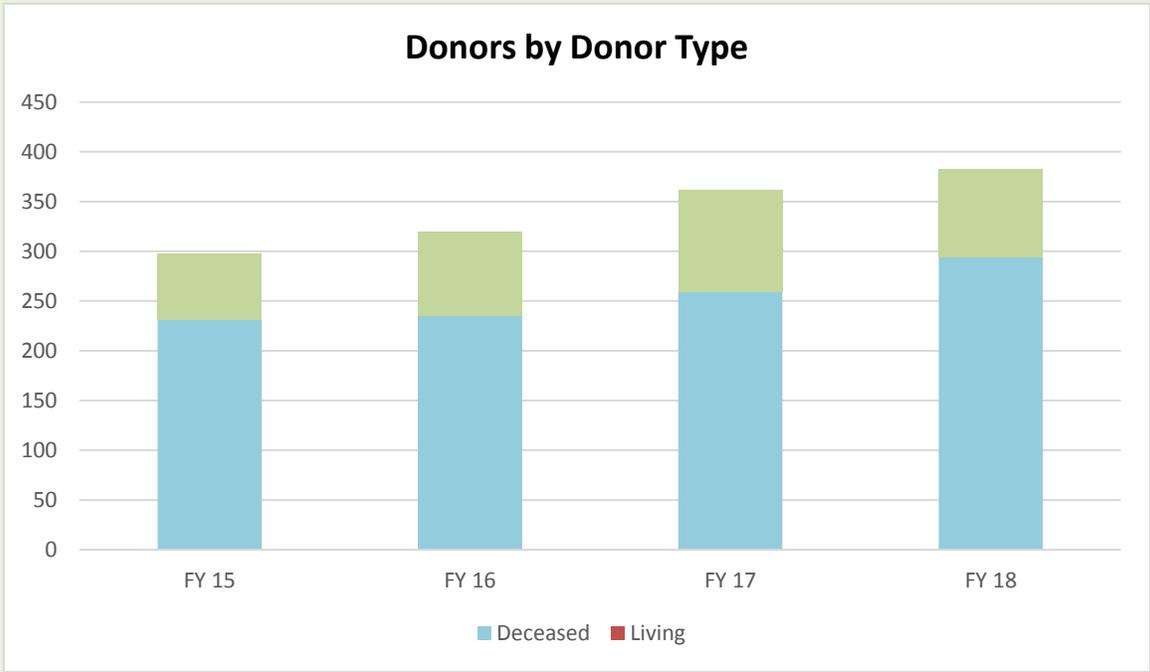
Number of men, women, and children on the national transplant waiting list with Missouri as home state as of July 2018.



**Deceased and Living Donors

More than 1,300 candidates with Missouri as their home state are waiting for a transplant according to Organ Procurement and Transplantation Network (OPTN). A breakdown by organ type for Missouri candidates on the waiting list follows; the total number of people waiting is less than the sum of organs due to patients listed in multiple categories.





Current data about deceased and living donors, including age, race/ethnicity, gender, and more available at [OPTN Data Reports](#).

648

Transplanted Organs

88

Living Donors

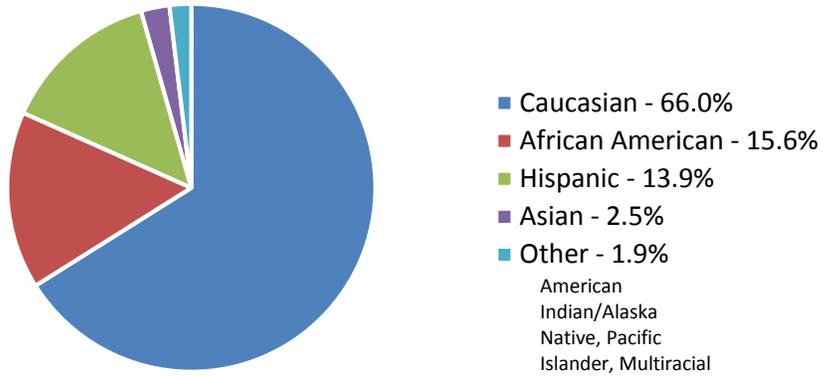
294

Deceased Donors

- Twenty-three percent of Donors in FY 18 were Living Donors.
- Thirty-four percent of deceased donors in 2017 were over the age of 50.
- Sixty percent of deceased donors in 2017 were male, 40 percent female.

Sixty-one waiting list registrations with Missouri as the candidate's home residence were removed from the waiting list because their condition deteriorated and were too sick to transplant. Additionally, 61 individuals died while waiting for a life-saving transplant.

Deceased Donors by Ethnicity (FY 2017)



For current statistics about deceased and living donors; including age, race/ethnicity, gender, state, and more, visit the [OPTN Data Reports \(https://optn.transplant.hrsa.gov/\)](https://optn.transplant.hrsa.gov/) for current statistics.

3,575,000+

Registered as potential organ, eye and tissue donors and 18 years of age or older.

Registered under the age of 18: 197,400+.

Total registered, including 538 out-of-state: 3,772,433.

Source: Missouri Donor Registry System

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.

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.

Finance

Partners encourage contributions to the Organ Donor Program Fund. The fund supports education, as well as registry maintenance and modification.

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.

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.

Partnering Agencies/Organizations



Established in 1996, the Governor’s Organ Donation Advisory Committee, a ten-member committee, assists the Department of Health and Senior Services (DHSS) and the Department of Elementary and Secondary Education (DESE) to develop awareness programs about organ, eye and tissue donation. The Committee collaborates with partners to educate the public about the importance of organ, eye and tissue donation; recommends expenditure priorities from the Organ Donor Program Fund; honors and recognizes donor family members for their loved one’s gifts; celebrates National Donate Life month; and submits a report of activities and recommendations annually. The Committee was instrumental in developing the statewide strategic plan along with collaborating agencies/organizations.



The Missouri Department of Revenue (DOR) serves as the central collection agency for state revenues. Primary responsibilities are tax collection, titling and registration of motor vehicles, and licensing of drivers. Over 98 percent of donor designations recorded in Missouri’s statewide registry are collected through DOR. DOR works with the DHSS to incorporate organ, eye and tissue donation information into electronic correspondence with local driver license office personnel. DOR is the lead agency for collecting donor designations, wording of the registry questions asked at the local license offices, encryption of data transfer to the Donor Registry System, and collection of fees for the “Be An Organ Donor” specialty plate. Their representative actively participates in the Governor’s Organ Donation Advisory Committee (GODAC) meetings and provides guidance to the Committee and DHSS.



The Missouri Department of Elementary and Secondary Education (DESE) partners with the organ, eye and tissue donation community to assist in the integration of educational initiatives within the public school setting. Integrating organ, eye and tissue donation information provides opportunities for students to learn of organ and tissue donation and be prepared to respond to the questions at the local license office when applying for a permit, driver, or non-driver license. DESE’s representative actively participates in GODAC meetings and provides guidance to the Committee and DHSS.



Midwest Transplant Network (MTN) has been connecting lives through organ donation since 1973. As the federally designated not-for-profit organ procurement organization (OPO) for Kansas and the western two-thirds of Missouri, MTN provides services, which include organ procurement and surgical tissue and eye recovery, laboratory testing, and 24-hour rapid response for referrals from hospital partners. MTN ranks in the top 10 OPOs nationally across several metrics, which reflects the organization's quality, professionalism, and excellence in partnerships throughout the region. For more information, visit mwn.org.



"We save lives through excellence in organ and tissue donation" is Mid-America Transplant's mission, a federally certified not-for-profit OPO. Mid-America Transplant's primary service offering is to facilitate and coordinate the organ, eye and tissue donation process for the eastern third of Missouri plus a small number of counties in Southwest Missouri and parts of Illinois and Arkansas. The OPO relentlessly pursues core values of compassion, quality, teamwork, innovation, and integrity to create a positive donation experience for donor families.



Saving Sight is a 501(c)(3) non-profit organization with a mission to change lives by saving sight. Founded in 1960, the organization introduced eye donation and the gift of sight to Missouri. One of their primary purposes is to facilitate cornea recovery and transplantation, working diligently to assure corneal transplants, eye health research, and increasing Registry enrollments. Stewardship of gifts, integrity, collaboration, teamwork, leadership, and accountability are their guiding principles.



The Missouri Kidney Program (MoKP) offers a number of educational opportunities for patients, families, renal social workers, and healthcare providers. A state funded program administered by the University of Missouri, School of Medicine, provides financial assistance for eligible Missourians who have kidney failure and are on dialysis, or have received a kidney transplant. The program supports education and research, collaborates with dialysis centers and transplant centers statewide, and has expertise in health insurance for kidney disease, including Medicaid and Medicare. The program participates in GODAC meetings, encourages registry enrollments, and actively supports all partners serving Missourians with kidney disease.



Gift of Life (GOL) is a national model for support, awareness, and success of organ, eye and tissue donation through education, mentoring, and collaboration with partners and individuals in the transplant community. The non-profit organization implements the Life Savers high school classroom program in eight Missouri counties and plans expansion through an online program known as Learn LifeSavers. The purpose is to encourage families to discuss organ, eye and tissue donation, build public awareness and acceptance about the value of donation, and reduce the number of patients waiting for a transplant. The Transplant Mentors program encourages patients to be their own best advocate and help navigate the transplant process. In addition, GOL offers trained speakers for spiritual communities, civic organizations, and businesses regarding the life value of organ, eye and tissue donation.



Health Care The mission of the University Hospital and Clinics' Emergency Medical Services (EMS) Education Institute is to provide an evolving and dynamic education and training program to new and existing EMS and Allied Healthcare Professionals that meets and exceeds the current standard of care. "Keep Hope Alive" is an educational training program initially developed by Sierra Donor Services. The Institute provides contact hours for those completing the training. The video training program and contact hours are available at no cost to participants. After successfully completing the program, DHSS submits information to the Institute who issues the contact hour. This training and contact hour is another way for EMS personnel to maintain Missouri licensure.



The Organ and Tissue Donor Program within the DHSS educates the public and brings awareness to the importance of giving life through organ, eye and tissue donation. The program is committed to promoting and maintaining a statewide registry, saving lives by providing individuals a means to record their donor designation, and providing the organ and tissue procurement agencies access to Registry records. Statewide and inter-state partnerships are essential to Missouri's success. The program provides direct support to GODAC, serves as the committee secretary, and publishes an annual report in January. Program staff work collaboratively with other organizations dedicated to saving lives through organ, eye and tissue donation. Missouri statutes further outline DHSS' responsibility (<https://health.mo.gov/living/organdonor/statutesandbills.php>).

The following pages provide progress summaries submitted by collaborating agencies outlined on pages 13-15. Fiscal year progress, and when appropriate, a data summary table, is found below the objectives.

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 (DRS) reporting features to provide timely data without compromising confidentiality.
Status: Behind Schedule	6/30/15: Request with information technology group. 6/30/16: Request with information technology group. DHSS program staff researching DRS options.
Progress Notes:	6/30/17: Request with information technology group. DHSS staff conducting environmental assessments prior to bidding out DRS.

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):	<ol style="list-style-type: none"> 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 post-test 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 Score	Avg. Post- Test Score
Fiscal year		
FY14	67.8 %	82.8%
FY15	80.4%	88.3%
FY16	83.7%	95.7%
FY17	80.0%	92.0%
FY18	81.0%	92.0%

Status: On Target	<p>6/30/14</p> <ul style="list-style-type: none"> 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. <p>6/30/15</p> <ul style="list-style-type: none"> Emergency Medical Technicians (EMTs) in Boone County are routinely encouraged to take the course by the University of Missouri (ongoing).
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- GODAC committee chair contacted CECMSW 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 KHA training. The KHA figure does not include training provided by Midwest Transplant Network.
- 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). Add this action to the next revision of the strategic plan.

6/30/2017

- Midwest Transplant Network has trained 541 emergency management technicians during nine training sessions in their service area utilizing a training they developed.

6/30/2018

- Pursuing NAEMT will not occur based on research by the GODAC, as it is cost prohibitive.
- Nineteen emergency personnel completed the *Keep Hope Alive* training in FY18 increasing knowledge from an average of 81 percent to 92 percent.
- Midwest Transplant Network continues to train emergency management technicians in their service area utilizing a training developed by their agency.

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): 1. By June 2018, develop and deploy a training program for all local license office employees about organ, eye and tissue donation and the donor registry system.

Number of registry enrollments among individuals 18 years of age and older				
6/28/2014	3,096,109	7/01/2017	3,447,998	
6/27/2015	3,207,558	6/30/2018	3,575,013	
7/02/2016	3,335,622			

Status: On Target

6/30/16

- Mid-America Transplant developed training and trained three offices for which they held the contract.
- Review objective and action steps during FY17/18.
- Eighty-nine local license offices in Midwest Transplant Network’s (MTN) service area received the monthly educational newsletter developed and published by their agency.
- Eighty-nine local license offices in MTN’s service area also received the “Licensed for Life” quarterly educational newsletter

developed and published by their agency.

- One hundred seventy-nine offices statewide received a quarterly newsletter from the DHSS. The newsletter contains information relevant to the local license offices about organ, eye and tissue donation.
- One hundred seventy-nine offices statewide received a copy of the Annual Report.

6/30/17

- During the fiscal year, Mid-America Transplant owned and operated three local driver license offices. Mid-America Transplant provided their license offices' staff with the needed resources, support and workshops to serve staff and the community, including training, dispelling myths and shadowing opportunities. Open communication was maintained to overcome challenges. Priority focus, based on data, was their three offices, Northside, Chesterfield, and Maplewood. Mid-America did not rebid on contract license offices for FY18.
- Beginning in January 2017, Mid-America began collaborating with other local license offices through newsletters, supplies, brochures, promotional items and visits. This included conversations and observation.
- Mid-America regularly monitors data to identify higher volume offices with below average enrollment rates to direct their focus.
- Eighty-two offices in Midwest Transplant Network's (MTN) service area received the monthly educational newsletter developed and published by their agency.
- Eight-two offices in MTN's service area received the "Licensed for Life" quarterly educational newsletter developed and published by their agency.
- MTN began developing an online training for offices in their service area; MTN expects the program to be available in FY18.
- MTN staff visited 40 license offices to deliver GODAC awards, offer recognition and appreciation and provide refresher training.
- MTN also awarded the Joplin License Office manager, Haley Pryor, with the 2017 Excellence in Donation award. Ms. Pryor's leadership and ability to create a positive and productive work environment that inspires and motivates employees lead to the office consistently registering 50 percent of their monthly customers and collecting over \$6,000 for the Organ Donor Program Fund. Staff consistently asked the mandatory questions.
- DHSS sent 178 offices a quarterly newsletter from DHSS containing information relevant to the license offices about organ, eye and tissue donation, including statewide GODAC awardees.
- DHSS sent 178 offices two copies of the Annual Report.
- DOR provided training to new and current license office staff through online manuals, electronic newsletters, and in person from regional coordinators regarding the importance of asking the donor questions as defined.
- DOR distributed weekly processing reminders and annual report information to the license offices during the months of January, March and April 2017.
- DOR provided DHSS a cumulative data report of the number of individuals consenting to being organ, eye, and tissue donors and of those, the count of individuals consenting to placement of the donor symbol.

6/30/2018

- DHSS distributed to 179 local license offices a quarterly electronic newsletter containing information relevant to the license offices about organ, eye and tissue donation, including statewide GODAC awardees.
- DHSS mailed 179 local license offices two copies of the Annual Report.
- During the fiscal year, Midwest Transplant Network (MTN) provided driver's license offices in their service area resources and promotional products to encourage customers to make an informed decision to say "yes" to registering their donation decision

while getting or renewing their driver’s license. In addition to providing customer resources, MTN provided license office staff educational resources such as a DMV quarterly print newsletter, monthly email dashboard, and professional trainings to help educate staff about the truths of donation. MTN also celebrated national observances like National Donate Life Month and National DMV Appreciation Week. MTN’s donor designation coordinator helped to motivate and inspire DMV staff through office challenges like their DMV #GotHeart Challenge for National Donor Day and their National Donate Life Blue and Green Day Photo Contest in April. During the second half of the fiscal year, MTN invested in DMV advertising in all offices where television advertising was available in an effort to quickly provide donation facts to educate customers and increase donor designation.

Priority Area Education – High School Education

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

Objective(s):
 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 modules options for public schools.

Note: Data does not include individuals 18 years of age, as these individuals are adults. Measure needs modification to reflect current data reports available in the DRS (15-17 year olds) in the next revision to the strategic plan (2020). Objective one written for all participating schools (Missouri and Kansas) and needs adjustment.

Students Reached:

6/28/2014 171,252
 6/27/2015 174,285
 7/2/2016 180,568
 6/30/2017 15,185 students and 24,634 total individuals
 6/30/2018 15,126 students and 26,538 total individuals (GOL) and 100 high school students (MTN)

High Schools:

2016-17: 104; 56 Missouri Schools
 2017-18: 114 Schools

Status: On Target

- 6/30/16
- 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 conducted 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.
- Teacher survey executed, data collected and data shared with the work group.
- Organ donation information session at state HOSA conference (March 2016).
- Currently the LifeSavers program is in eight Missouri counties: Adair, Benton, Cass, Jackson, Platte, Clay, Lafayette and Ray.
- Action step(s) dates need modification and published in the next time revisions of the plan (2020).
- Review objectives in FY 2017.

6/30/2017

- Objective one needs modification to reflect Missouri numbers only and not all participating schools from Kansas and Missouri. Currently the program is in 56 Missouri high schools.
- Objective two target date extended to 2019. The work team is focused on expanding the LifeSaversSM program already available in part of the state.
- The High School Education work team accomplishments
 - Planned and implemented seven student focus groups at the March 2017 HOSA Conference.
 - Focus groups results reviewed, summarized and shared with the work team.
 - Donate Life America Youth Education Survey Summary reviewed and full report requested.
 - FY18 fall meeting schedule planned.
- Mid-America Transplant provided 31 education programs and educated approximately 800 high school students from 25 public schools during the 2016-2017 public school academic year.
- Donate Life Globe bookmarks developed, printed and distributed through the DHSS warehouse. Bookmarks distributed at the spring 2017 HOSA conference.
- DHSS staff provided education to high school students, in collaboration with partners, at the 2017 HOSA conference exhibit booth.

6/30/2018

- HB 2129 introduced, modified, and passed during the 2018 legislative session. Governor Michael L. Parson signed the bill on July 5, 2018.
- The High School Education Outreach Committee and Gift of Life (GOL) successfully:
 - Met multiple times over the fiscal year to discuss program content, HB 2129 status, and partner actions.
 - Named the online program Learn LifeSavers.
 - Secured funding from various sources to assist in the development of a microsite within GOL's website, and for the development of two 2-3 minute videos.
 - Drafted teacher lesson plans (GOL).
 - Next Steps: Review of teacher lesson plans and set target launch date.

- GOL recommends the following objective changes for the FY19 strategic plan.

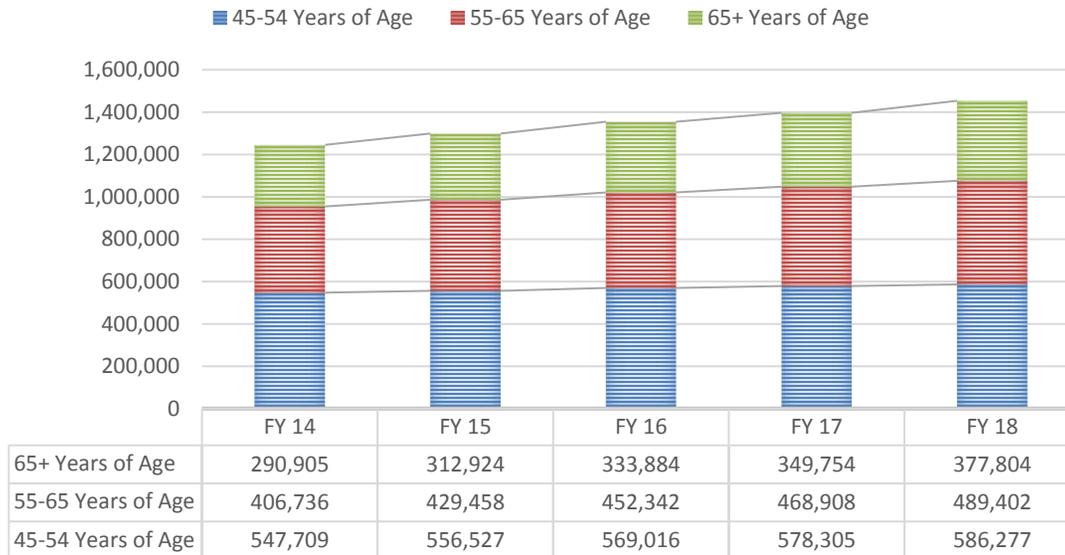
- Delete current objectives and replace them with the following:
 - By June 2019, increase the number of Missouri high schools implementing the LifeSavers classroom program from 54 schools to 60 schools.
 - By August 2019, offer Learn LifeSavers online program (LearnLifeSavers.org); a 30-minute lesson plan for teachers.
 - By June 2021, complete presentations of the Learn LifeSavers online program to all 525 Missouri School Boards
- Midwest Transplant Network provided five educational programs and educated over 100 high school students.

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.

DONOR REGISTRY SYSTEM DATA, BY AGE



Number of registry enrollments among individuals 55 years of age and older

Status: On Target

6/28/2014: 697,641 7/01/2017: 818,662
 6/27/2015: 742,382 6/30/2018: 867,206
 7/02/2016: 786,226
 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

- 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 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 designed and distributed to local license offices and public libraries.

6/30/17

- Team Missouri is reorganizing and it is unknown if this will be a focus of the team in FY18.
- DHSS aired a 30-second radio PSA developed by HRSA during April 2017.
- DHSS will not be focusing solely or directly on the 50 years of age and older group in FY18.
- Toward this priority area, Mid-America Transplant has utilized staff and volunteers to participate in over 20 community events, including health fairs and local license office registry drives.
- Saving Sight continues to educate about donation with Lions Clubs of Missouri by providing brochures, information and encouraging them to hold donor designation events.

6/30/2018

- DHSS aired a 30-second "What If" radio campaign originally developed by Illinois, and modified for Missouri with permission.
- Midwest Transplant Network has provided eight educational programs to over 150 seniors in their service area.

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.

6/30/16

Status: On Target

- 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 (MTN) reported 509 Facebook posts to their web page, 127 Tweets and seven new YouTube videos.

- MTN reported 8,133 Facebook likes, 1,005 Twitter followers and 3,927 You Tube views.

6/30/17

- DHSS continues to review and update website information related to organ, eye and tissue donation (www.health.mo.gov/organdonor).
- MTN reported 320 Facebook posts, 84 Tweets and added two (2) new YouTube videos to their website.
- Mid-America Transplant reported 370 Facebook posts and 363 Tweets.
- Saving Sight reported 154 Facebook posts and 305 Tweets to their website.
- Team Missouri reported 18 Facebook posts.

6/30/2018

- DHSS continues to review and update website information related to organ, eye and tissue donation (www.health.mo.gov/organdonor).
- DHSS published 18 Facebook posts and 20 Twitter messages during Donate Life Month (April 2018).
- DHSS published three Facebook posts and four Twitter messages during the annual Donor Family Recognition Program held at the Missouri State Capitol in April 2018.
- Midwest Transplant Network has expanded its engagement with the community through numerous social media channels. Not only has MTN greatly improved its communication and following on Facebook, Twitter, and LinkedIn, but they have created a new YouTube channel and begun outreach through Instagram. Video engagement has exponentially increased.

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.

6/30/2016

- 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.
 - Three hundred and thirty-eight participants and their families reached.
 - Mid-America Transplant’s award extended through FY17.

6/30/2017

Status: On Target

- Team lead identified three Springfield, Missouri UMC churches.
- Donor Sabbath celebrated in November 2016
 - MTN provided churches in their service area with National Donor Sabbath materials and training.
 - Mid-America Transplant provided two churches in their service area with materials and display items. In addition, they participated in collaboration with Saving Sight, in a candlelight memorial ceremony in Springfield, Missouri.
- DHSS renewed the award with Mid-America Transplant to provide education; turnover of staff prevented the contractor from reaching its goal during year two. The organization is committed to the effort and is in the process of hiring a full-time person to dedicate to the program for year three (FY18).
- Toward this goal and objective Saving Sight has participated in a candlelight memorial ceremony with Mid-America Transplant in

March 2017 at Campbell United Methodist Church in Springfield, Missouri.

6/30/2018

- Mid-America Transplant has indicated they will sustain educational efforts in minority communities through faith-based efforts as year three of the contract expires without renewal.
 - Three churches received the program.
 - Fifty-seven individuals participated.
 - Four churches plan to participate in FY19 (one already completed with 27 participants and five registrations).
- Midwest Transplant Network provided churches in their service area with National Donor Sabbath materials and training.

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.

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.

6/30/2017

- Toward this goal, MTN published a living kidney donor brochure, established a Living Donor email address for inquiries (LDonor@mwtn.org) and continues to feature stories of living donors on social media and other marketing materials.
- Saving Sight adopted a new brochure about organ, eye and tissue donation that includes information about living donation.
- Living donor data included in the annual report.

Status: On Target

6/30/2018

- DHSS activities included:
 - Living donor data included in the 2017 annual report.
 - Added United Network of Organ Sharing Living Donation link to the Organ and Tissue Donor Program's Donation Types webpage (July 2017).
 - Added indicator to hospitals participating in paired kidney donation to the Transplant Hospitals listing available on the Organ and Tissue Donor Program's Resources webpage (July 2017).
 - Added link to UNOS Transplant Living's Living Donation Costs to the Financial Resources available on the Organ and Tissue Donor Program's Resources webpage (February 2018).
 - Added Link to UNOS Transplant Living's Kidney Transplant Learning Center, which includes information on living

donation, to the Healthcare Resources available on the Organ and Tissue Donor Program’s Resources webpage (March 2018).

- Added UNOS Kidney Paired Donation: How it Works to the Kidney Paired Donation available on the Organ and Tissue Donor Program’s Donation Types webpage (March 2018).
- Toward this goal, Midwest Transplant Network provides a Living Kidney Donor Brochure and a Living Donor email address for inquiries (LDonor@mwtn.org). MTN continues to feature stories of living donors on social media and other marketing materials.
- During the 99th General Assembly, Missouri lawmakers passed HB 1953. The bill directed DHSS to develop and disseminate information regarding the bone marrow registry. Material is under development and is expected to be published on the web in FY19.

Priority Area Finance – Sustainability

Goal: Sustainable funding supports Donor Registry System operation and educational programs.

Objective(s):

1. By close of 2017 legislative session, reauthorize the Missouri Income Tax check off.
2. By June 2018, ensure a continual fund balance of three years of operating expenses.
3. By June 2018, establish an online contribution mechanism for the Organ Donor Program Fund.

Note: Annual reports are available at <http://www.health.mo.gov/living/organdonor/publications.php>.

6/30/2014

- FY 13 Organ Donor Program Fund report published in the Annual Report.

6/30/2015

- FY 14 Organ Donor Program Fund report published in the Annual Report.

6/30/2016

- While GODAC was trying to learn 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 to repeal the sunset clause. Representative Love will be sponsoring the house bill (HB 1673). Both bills, submitted with the same language, is seen as a consent bills.
- SB 738 pre-filed on December 1, 2015.
- Monitoring income and expenditures to assure the fund can support the current budget year plus three years of program operating expenses.
- FY 15 Organ Donor Program Fund report published in the Annual Report.
- Sunset Clause Repeal of the Income Tax Checkoff did not pass.

6/30/2017

- SB 248 sponsored by Senator Will Kraus and HB 105 sponsored by Representative Warren Love, identical bills, were pre-filed in December 2016 and written to repeal the sunset date in Statute 143.1016. HB 105 passed and reported to the Senate. SB 248 passed and signed by Governor Eric Greitens on June 20, 2017. GODAC Chair, Deb Simaitis, was present for the signing.
- Monitoring income and expenditures to assure the fund can support the current budget year plus three years of program operating expenses.

Status: On Target

- FY 16 Organ Donor Program Fund report published in the annual report.
- 6/30/2018
- Monitoring income and expenditures to assure the fund can support the current budget year plus three years of program operating expenses.
 - FY 17 Organ Donor Program Fund report published in the annual report.

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.

Note: Annual reports are available at <http://www.health.mo.gov/living/organdonor/publications.php>.

Status: On Target

6/30/2014

- Quarterly reports to the advisory committee completed and included income, expenses, and variance.
- FY 13 Annual budget report posted in the annual report.

6/30/2015

- Quarterly reports to the advisory committee completed and included income, expenses, and variance.
- FY 14 Annual budget report posted in the annual report.

6/30/2016

- Quarterly reports to the advisory committee completed and included income, expenses, and variance.
- FY 15 Annual budget report posted in the annual report.

6/30/2017

- Quarterly reports to the advisory committee completed and included income, expenses, and variance.
- FY 16 Annual budget report posted in the annual report.

6/30/2018

- Reports to the Committee during conference calls and face-to-face meetings. Reports included income, expenses, and variance, and trends.
- FY 17 annual budget report included in the annual report.

Priority Area Registry – Functionality

Goal: A confidential and technologically current Donor Registry System.

Objective(s): 1. By December 2017, Donor Registry System will be mobile friendly.
2. By June 2018, streamline the registration process of the Donor Registry System.

Status: Behind Schedule

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. Review process began for reporting feature updates. Pending submission 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.
- 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 DCPH 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 gathered by Organ and Tissue Donor Program staff.
- Proposals written and submitted to DHSS management for alternatives to the existing Missouri Donor Registry System.

6/30/2017

- DHSS Division of Community and Public Health (DCPH) management reviewed proposals and met with Organ and Tissue Donor Program team and supervisors.
- DHSS DCPH management made the decision to move forward with bidding out the DRS.
- Program staff began preparing a pre-project Customer Service Request (CSR) during June 2017 to the Office of Administration Information Technology Services Division (ITSD) for "Preparation of DRS Bid Document." The CSR to route through approval processes in early FY18 to ITSD.
- Organ and Tissue Donor Program staff prepared for environmental assessments. Meeting dates/times established with Midwest Transplant Network, Saving Sight, and Mid-America Transplant.

6/30/2018

- Organ and Tissue Donor Program staff completed the following environmental assessments:
 - DRS functional assessment;
 - Registry website reviews;
 - Organ procurement organizations/tissue bank assessment;

- Organ and Tissue Donor Program assessment; and
- Other state government request for proposals/bid documents and/or contracts.
- Organ and Tissue Donor Program staff began working with ITSD in a structured discovery process. Completion of the discovery process and the start of modernization of the Donor Registry System expected in FY 2019.
 - Reviewed high-level system processes presented by ITSD and made clarifications.
 - Completed vendor assessments about potential vendors.
 - Reviewed High Level System Requirements developed by ITSD.
 - Responded to DRS Requirements Matrix (Need vs. Requirement, Desires, Dependencies, Other States with Similar Functions, Risks and Benefits; potential vendor can meet/not meet, etc.

Priority Area Stakeholders – Communication

Goal: Engaged stakeholders making recommendations for Donor Registry System operations and education initiatives through open and transparent communication.

Objective(s):

1. By June 20, 2015, document roles of primary stakeholders.
2. By June 30, 2015, document communication process between the advisory committee and the Department.
3. 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:
 - September 6, 2012
 - November 30, 2012
 - February 19, 2013
 - April 4, 2013
 - May 23, 2013

6/30/2014

Status: On Target

- 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:
 - July 25, 2013.
 - September 27, 2013.
 - December 23, 2013.
 - February 21, 2014.
 - 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:
 - Language updated to current terminology.
 - 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:
 - July 17, 2014.
 - September 25, 2014.
 - December 9, 2014.
 - March 6, 2015.
 - May 28, 2015.

6/30/2016

- Most GODAC members completed annual training.
- Citizen group has temporarily suspended drafting statute changes until the sunset clause on the tax bill receives 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:
 - July 22, 2015.
 - September 23, 2015.
 - December 10, 2015.
 - March 4, 2016.
 - June 8, 2016.

6/30/2017

- Most GODAC members completed annual training.
- Review and update of training planned for FY18.
- Committee and partners reviewed, revised and approved the revised statewide strategic plan in June 2017.
- Advisory committee meetings/conference calls held:
 - September 8, 2016
 - December 1, 2016
 - March 8, 2017
 - April 11, 2017 (Capitol Day and Donor Family Recognition Program)
 - April 21, 2017 (Vote on program budget revisions)
 - June 29, 2017

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- Advisory committee meeting minutes posted to <http://health.mo.gov/information/boards/organdonor/meetingminutes.php>. 6/30/2018
 - Seven of the 10 positions have serving members; all but one are serving on expired terms.
 - Most GODAC members completed annual training.
 - General content update made in December 2017; checked links, added to timeline, updated out of date graphics, and added information about new materials available. Additional revisions planned for FY19.
 - Committee and partners reviewed the FY17 Strategic Plan Report published at <https://health.mo.gov/living/organdonor/publications.php>.
 - Subcommittee of members, partners, and the Organ and Tissue Donor Program staff will begin developing a new strategic plan to replace the current plan that expires June 30, 2019. Toward this effort, program staff began the process to secure a strategic plan facilitator.
 - Advisory committee meetings/conference calls held:
 - September 21, 2017
 - November 29, 2017 (Boards & Commissions Report)
 - December 6, 2017
 - March 5, 2018
 - March 9, 2018 (HB 2548, filed as a result of Boards & Commissions Report)
 - April 10, 2018 (Capitol Day and Donor Family Recognition Program)
 - June 14, 2018
 - Advisory committee meeting minutes posted to <http://health.mo.gov/information/boards/organdonor/meetingminutes.php>.

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

ⁱⁱ Organ Procurement and Transplantation Network (OPTN). (November 28, 2017). Data Reports and Policies. Retrieved from <https://unos.org/data/>

^{lii} U.S. Department of Health & Human Services. September 2018. Retrieved from <https://www.organdonor.gov/statistics-stories/statistics.html>.