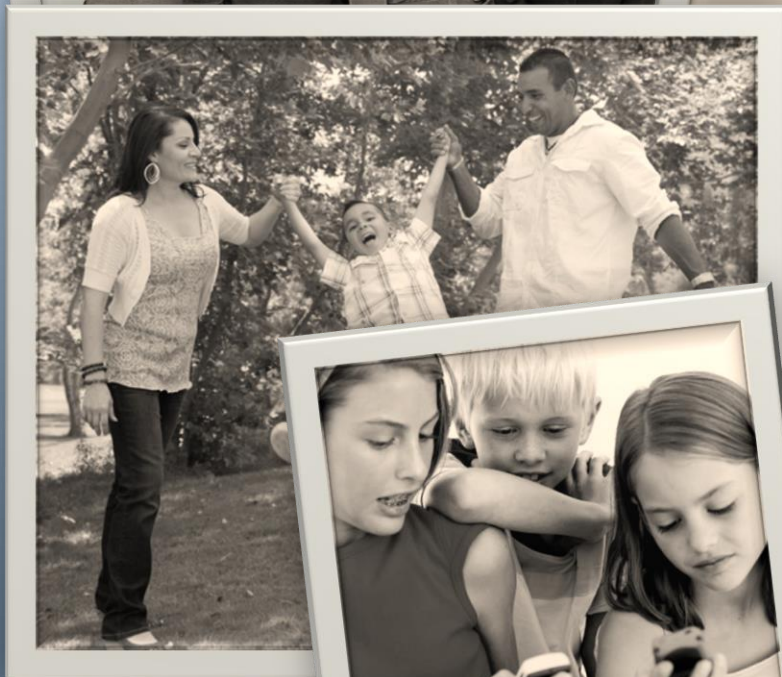


# *Saving and Enhancing Lives*

*Through Organ, Eye and Tissue Donation –*

*A Strategic  
Approach for  
Missouri*



FY17 Status Report

12/1/2017



The FY17 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](http://www.health.mo.gov/organdonor)

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. 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; 116,109 people and of those, 75,443 people are active waiting list candidates.<sup>i</sup> 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 can be accessed 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](http://www.health.mo.gov/living/organdonor/publications).

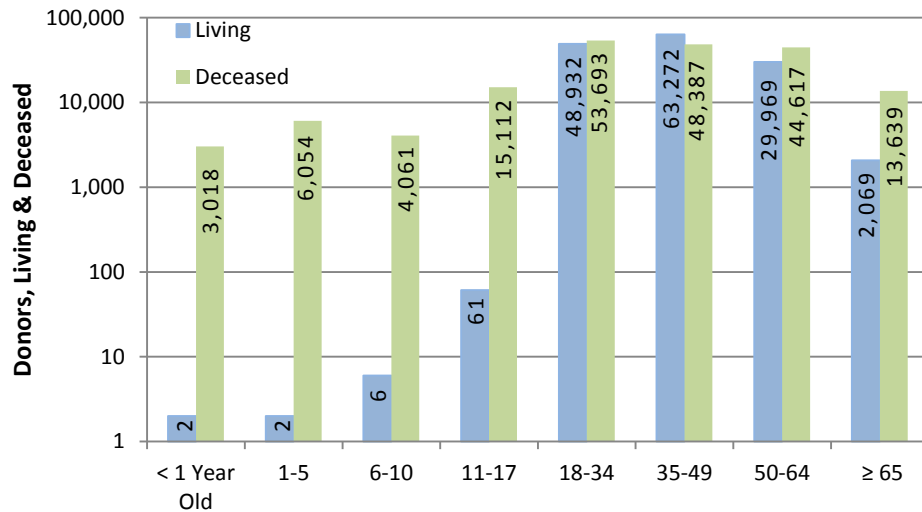
## National Data

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.<sup>ii</sup>

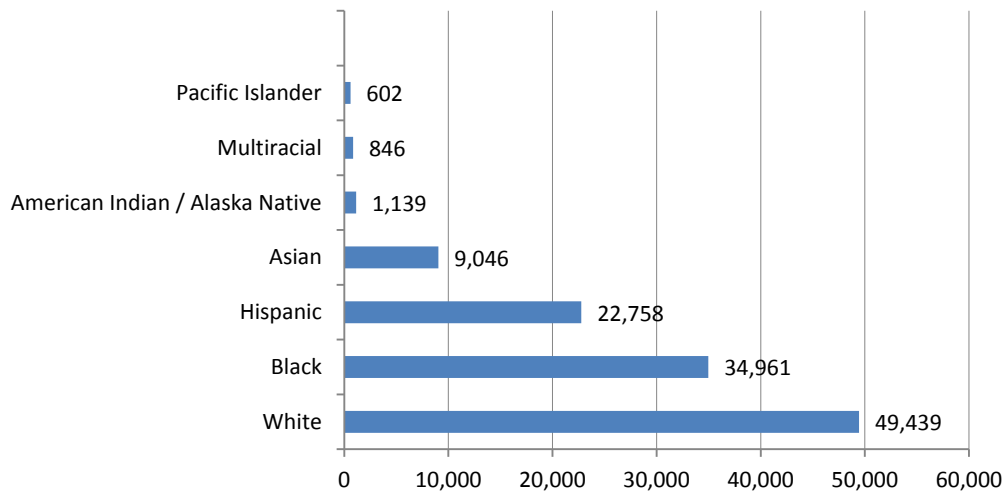
### U.S. Organ Donors by Donor Type by Age

Jan 1998 - Sept 2016



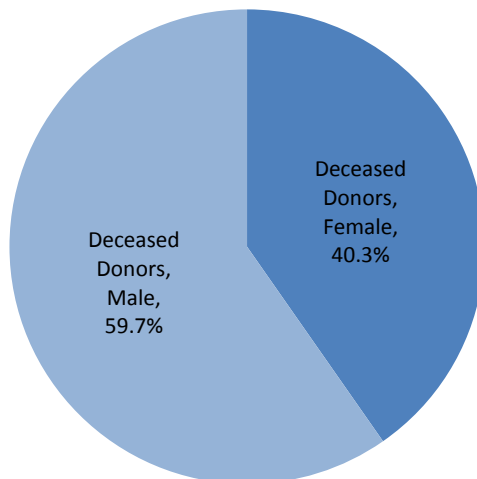
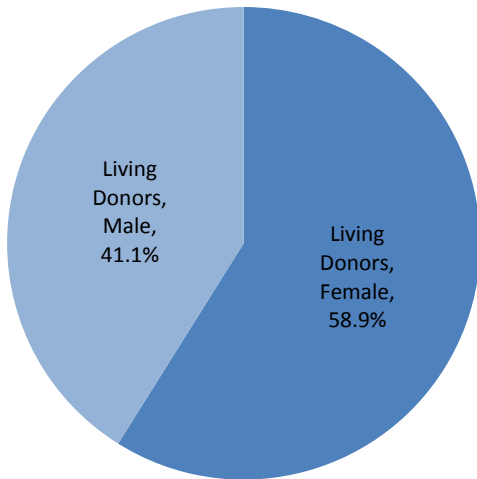
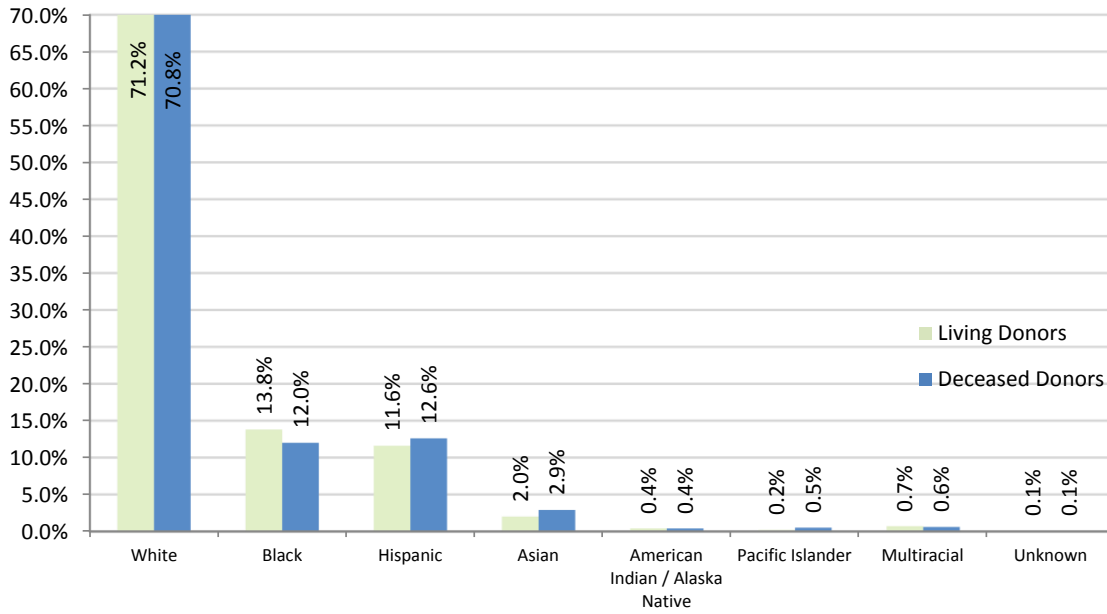
### U.S. Waitlist by Race/Ethnicity

Based on OPTN data as of February 20, 2017



# U.S. Donors

Jan 1988 - Sept 2016

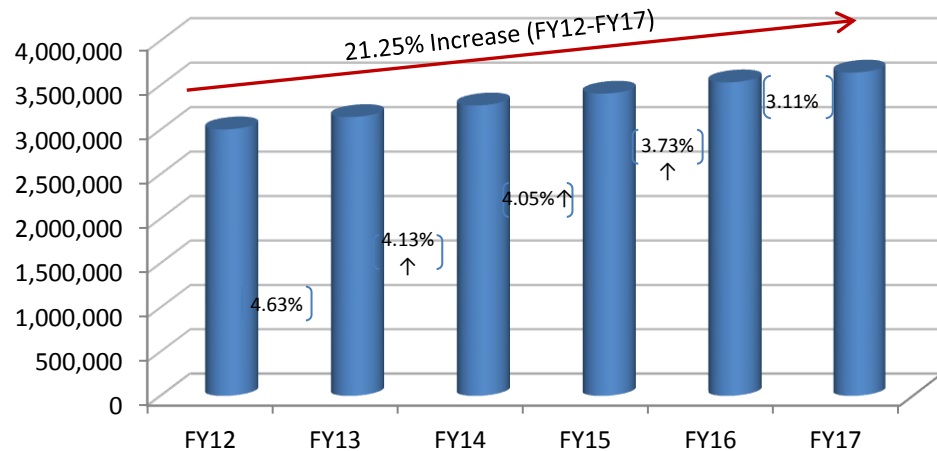


## Missouri Data

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 2017, 3,653,812 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 and later combined. The fluctuation in driver's license transactions can range from 115,600 to 153,000 a month.<sup>iii</sup> At the close of the 2016 calendar year, Missouri's donor designation rate (DDR) at local license offices was 50 percent; an increase over the previous year of 47 percent<sup>iv</sup>. According to the 2017 Annual Report of Donate Life America, Missouri had the highest increase in DDR for Region III in calendar year 2016: six percent.<sup>iv</sup>

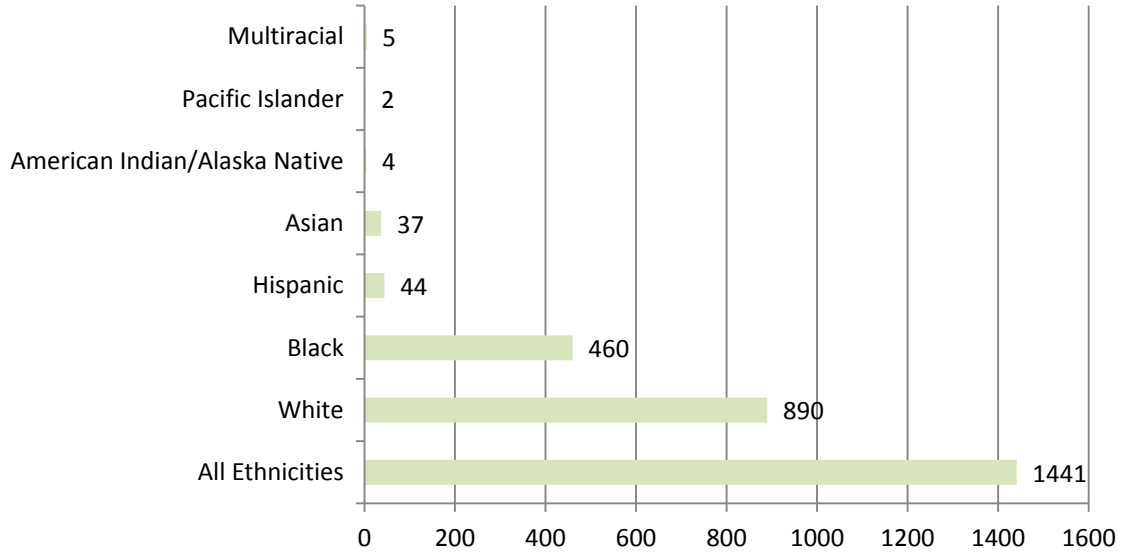
**Missouri Residents Registered as Organ, Eye and Tissue Donors**  
Missouri Donor Registry System as of July 1, 2017



Missouri's population demographic breakdown; Whites 84.6 percent, Blacks 12.5 percent and Other 2.9 percent.<sup>v</sup> 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.<sup>vi</sup>

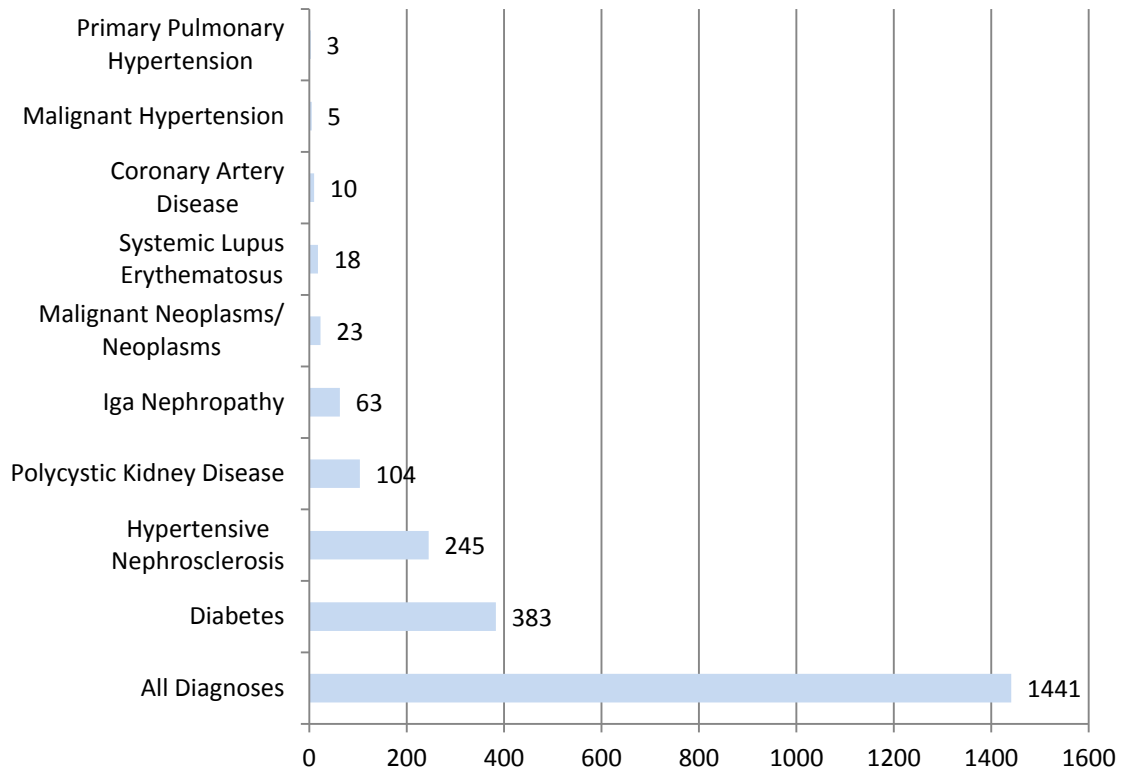
### Missouri Waitlist: Candidates by Race/Ethnicity

Based on OPTN data as of February 20, 2017



### Missouri Waitlist: Candidates by Diagnosis

Based on OPTN data as of February 20, 2017





# Missouri Registrants

## 3,526,961



Male: 46.9%      Female: 53.1%

### 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   | 595,953              | 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%                                 |
| <b>Total Registrants</b>                            | <b>3,526,961</b>     |                  |  |
| <b>Total Population Est.</b>                        |                      | <b>6,083,672</b> |  |
| <b>Total Percent of State Population Registered</b> |                      |                  | <b>57.97%</b>                          |

### 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>)



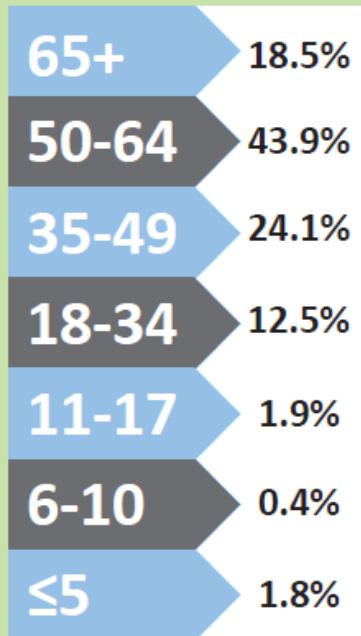
# MISSOURI SNAPSHOT



**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

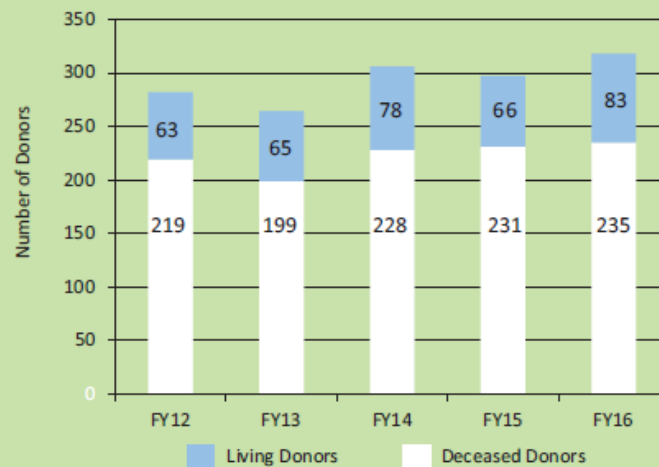


## Missouri Registrants Ever Waiting by Age by Fiscal Year

|              | 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          |
| <b>Total</b> | <b>2,310</b> | <b>2,443</b> | <b>2,328</b> | <b>2,327</b> | <b>2,317</b> |

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)

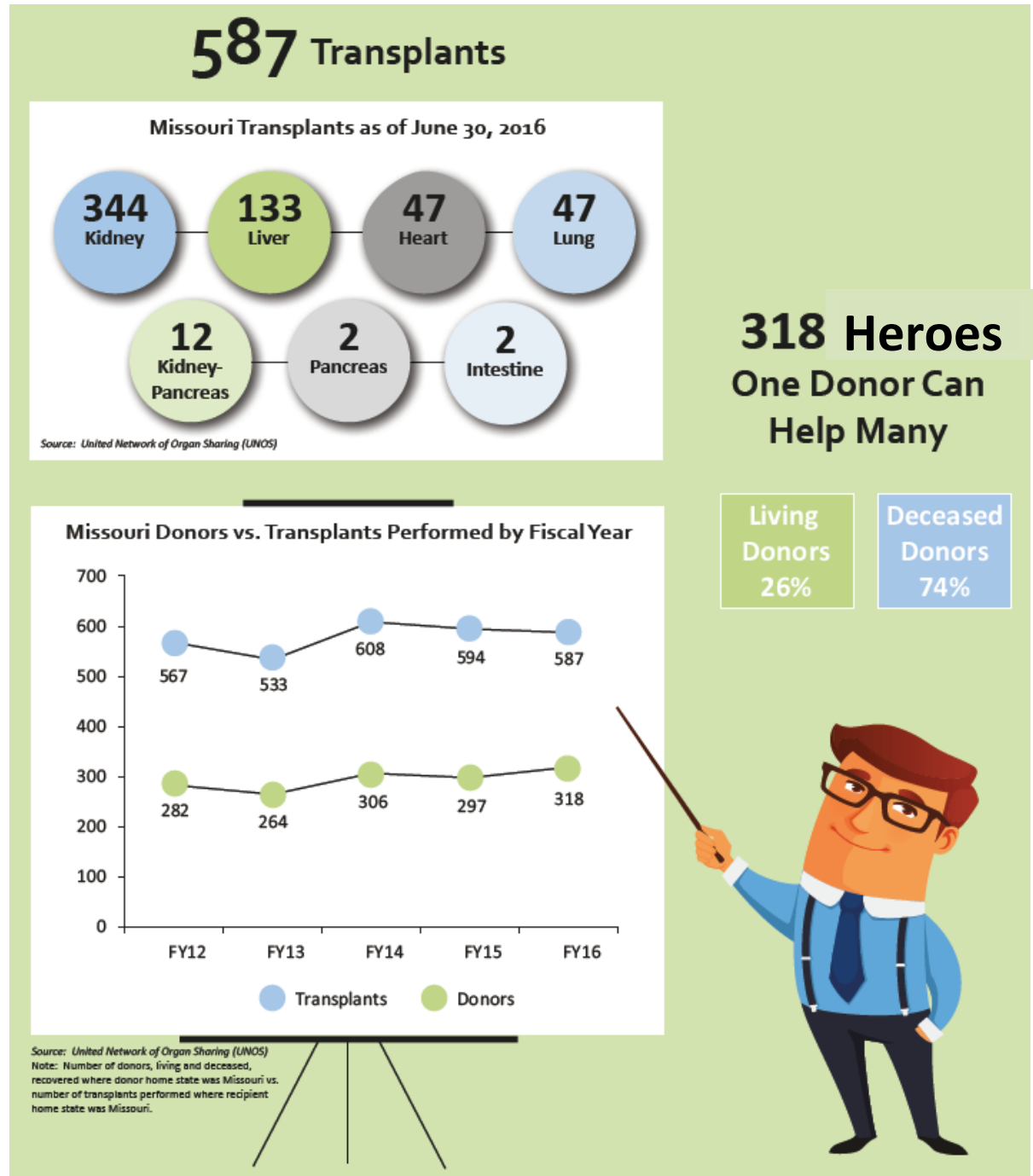
## Recovery Authorized by the Registry

|                   | 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/Cornea 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>)

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.



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>)

# *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**

|                        |  |
|------------------------|--|
| <b>Goal:</b>           | Accurate and relevant data used to make informed decisions.  |
| <b>Objective(s):</b>   | 1. By June 2018, upgrade Donor Registry System (DRS) reporting features to provide timely data without compromising confidentiality. |
| <b>Status: Behind</b>  | 6/30/15: Request with information technology group.  |
| <b>Schedule</b>        | 6/30/16: Request with information technology group. DHSS program staff researching DRS options.                                      |
| <b>Progress Notes:</b> | 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)**

|                      |   |
|----------------------|---|
| <b>Goal:</b>         | Educate and build awareness about organ, eye and tissue donation so people can make an informed decision.   |
| <b>Objective(s):</b> | <ol style="list-style-type: none"> <li>By June 2017, increase from zero to 500 the number of emergency management personnel that complete the <i>Keep Hope Alive</i> training.</li> <li>By June 2017, increase knowledge among emergency management personnel as measured by <i>Keep Hope Alive</i> training pre- and post-test scores.</li> <li>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.</li> </ol> |

| Fiscal year | Avg. Pre-Test Score | Avg. Post-Test Score |
|-------------|---------------------|----------------------|
| FY 14       | 67.8 %              | 82.8%                |
| FY15        | 80.4%               | 88.3%                |
| FY16        | 83.7%               | 95.7%                |
| FY17        | 80.0%               | 92.0%                |

**Status: On Target**

6/30/14

- 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 (*Deb Simaitis, donor mother*).
- 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 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). This action will be added 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.

**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 |
| 6/27/2015 | 3,207,558 |
| 7/02/2016 | 3,335,622 |
| 7/01/2017 | 3,447,998 |

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.
- 89 local license offices in Midwest Transplant Network’s (MTN) 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 receive a quarterly newsletter from the Department of Health and Senior Services (DHSS). The newsletter contains information relevant to the local license offices about organ, eye and tissue donation.
- 179 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 Fiscal year 18.

- 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 (82) offices in Midwest Transplant Network's (MTN) service area received the monthly educational newsletter developed and published by their agency.
- Eight-two (82) 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 and is expected 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.
- The Department of Revenue (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.
- Department of Revenue (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.

**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 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. Objective one is written for all participating schools (Missouri and Kansas) and needs to be adjusted.*

**Status: On Target**

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

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 were 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 to be modified by the workgroup and published in the next time revisions of the plan.
- Objectives to be reviewed in FY 2017.

6/30/2017

- Objective one needs to be altered 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 date was extended to 2019. The work team is working to expand the LifeSavers<sup>SM</sup> 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.

**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.

**Status: On Target** 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](http://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 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](http://www.health.mo.gov/organdonor).
- "8 Truths" poster being designed for distribution 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 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.

## 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

- 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](http://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 and 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

**Status: On Target**



([www.health.mo.gov/organdonor](http://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.

## 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.

6/30/16

- 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

**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/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.

## 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

**Status: On Target**

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 completed a living kidney donor brochure, established a Living Donor email address for inquiries ([LDonor@mwtn.org](mailto: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.

## 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

- 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 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 were submitted with the same language and were 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.

**Status: On Target**

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. The bills were written to repeal the sunset date in Statute 143.1016. HB 105 passed and was reported to the Senate. SB 248 passed and was signed by Governor Eric Greitens on June 20, 2017. GODAC Chair, Deb Simaitis, was present for the signing.
- Organ Donor Program Fund report published in the Annual Report.

## Priority Area Finance – Stewardship

**Goal:** Transparent stewardship of the Organ Donor Program Fund.

|                          |  |
|--------------------------|--|
| <b>Objective(s):</b>     | 1. By June 2018, provide budget reports to advisory committee, partners and the public.  |
|                          | <i>Note: Annual reports are available at <a href="http://www.health.mo.gov/living/organdonor/publications.php">http://www.health.mo.gov/living/organdonor/publications.php</a>.</i>  |
|                          | 6/30/2014 <ul style="list-style-type: none"> <li>• Quarterly reports to the advisory committee completed and included income, expenses and variance.</li> <li>• Annual budget report posted in the annual report.</li> </ul> |
| <b>Status: On Target</b> | 6/30/2015 <ul style="list-style-type: none"> <li>• Quarterly reports to the advisory committee completed and included income, expenses and variance.</li> <li>• Annual budget report posted in the annual report.</li> </ul> |
|                          | 6/30/2016 <ul style="list-style-type: none"> <li>• Quarterly reports to the advisory committee completed and included income, expenses and variance.</li> <li>• Annual budget report posted in the annual report.</li> </ul> |
|                          | 6/30/2017 <ul style="list-style-type: none"> <li>• Quarterly reports to the advisory committee completed and included income, expenses and variance.</li> <li>• Annual budget report posted in the annual report.</li> </ul> |

**Priority Area Registry – Functionality**

|                                |  |
|--------------------------------|--|
| <b>Goal:</b>                   | A confidential and technologically current Donor Registry System.  |
| <b>Objective(s):</b>           | 1. By December 2017, Donor Registry System will be mobile friendly.<br>2. By June 2018, streamline the registration process of the Donor Registry System.  |
|                                | 6/30/2013 <ul style="list-style-type: none"> <li>• Donor Registry System Mobile Enrollment Component survey conducted to determine usage and viability.</li> </ul>   |
|                                | 6/30/2014 <ul style="list-style-type: none"> <li>• Donor Registry System Maintenance Customer Service Request (CSR) completed and reviewed with Office of Administration Information Technology Services Division (ITSD) representative.</li> <li>• Donor Registry System Report Survey of users to determine usage, satisfaction and future reporting needs.</li> <li>• CSR drafted and began review process for reporting feature updates to be submitted to ITSD.</li> </ul>  |
| <b>Status: Behind Schedule</b> | 6/30/2015 <ul style="list-style-type: none"> <li>• CSR for confirmation letter updates submitted through the established DHSS Division of Community and Public Health (DCPH) process to ITSD. Request completed.</li> <li>• CSR for reporting feature updates submitted through the established DHSS DCPH process to ITSD.</li> <li>• CSR for intent records, profile and processes modification requested submitted through the established DHSS DCPH process to ITSD.</li> <li>• CSR for reporting feature updates re-submitted and included Spanish language updates to online enrollment process through the established DHSS DCPH process to ITSD.</li> </ul> |

- 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 being 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 is expected to route through approval processes in early FY18 before being forwarded to ITSD.
- Organ and Tissue Donor Program staff prepared for environmental assessments expected to be completed in FY18. Meeting dates/times were established with Midwest Transplant Network, Saving Sight and Mid-America Transplant.

**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

**Status: On Target**

6/30/2014

- Committee utilizes the SBAR (Situation, Background, Assessment and Recommendation/Requests) format to communicate with

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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 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:
  - July 22, 2015.
  - September 23, 2015.
  - December 10, 2015.
  - March 4, 2016.
  - June 8, 2016.

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6/30/2017

- Most GODAC members completed annual training.
- Training to be reviewed and updated in 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
- Advisory committee meeting minutes posted to <http://health.mo.gov/information/boards/organdonor/meetingminutes.php>.

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

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

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

<sup>iv</sup> Donate Life America 2017 Annual Update

<sup>v</sup> Department of Health and Senior Services. (January 28, 2015). Population MICA. Retrieved from [health.mo.gov/data/mica/mica/population.php](http://health.mo.gov/data/mica/mica/population.php), November 14, 2016

<sup>vi</sup> 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

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.