



Governor’s Organ Donation Advisory Committee Minutes

June 7, 2019



Note taker (s): Valerie Volkart
Attendees: Joan Keiser, Deb Simaitis, Peter Nicastro, Phil Duncan, Kenny Kovacs, Kim Harbur, Valerie Hardesty, Shelly Wehmeyer, Laura Beckman, Kevin Lee, Nicole Kellen, Sandy Hentges, Jim Pruitt, Steve Cramer, Virginia Beatty, Valerie Volkart, Bret Simmons, Ron Steinkamp
 By phone: Jan Finn, Gina Wisch
Called by: Joan Keiser, Chair
Called to order at: 10:07 a.m.

Welcome, Introductions, Agenda Approval and Minute Approval

Ms. Keiser gave the welcome and introduced Bret Simmons and Ron Steinkamp who represent the strategic plan contractor agency, Brown Smith Wallace. No additional introductions were needed.
 The agenda was approved with two changes: remove Sharp Media Group Data Report, as Mid-America Transplant did not renew the contract; and add Driver License Renewal Notice to the end of New Business.
 March 13, 2019 minutes were approved with the following corrections: correct spelling of Laurie Hines’ name in the Attendees section and move the second sentence under the Proclamation report to the Capitol Day & Donor Family Recognition report.

Action Items:	Person Responsible:	Deadline:
Correct the minutes for March 13, 2019	Program Staff	Completed

Reporting of Officers/Committees

Chair Report

- Ms. Keiser reported that she called Steve Cookson to obtain a mailing address for his resignation acceptance/thank you letter. Mr. Cookson hopes to do more in the future, but due to his health concerns, the timeframe for his availability is unknown. Ms. Keiser will check in with him periodically.
- There has been no change in the status of GODAC applications for appointment; Ms. Beatty suggested that individuals who submitted applications continue to call the Boards and Commissions office for a status update. Mr. Nicastro suggested that individuals reach out to their local legislators for assistance and leverage the voice of their employer.

Dashboard and Financial Trend Updates

- Mr. Nicastro provided an overview of the reports and reviewed the trend of contributions, enrollments, events and the registry downtime. The fund balance at the end of May was \$723,581.00. The contribution rate at the local license offices has increased to 7.2%, which is an increase of approximately 2%. The consent trend has also increased; as of June 2nd, there are 3,102,911 adults (18 years of age and older) on the consent registry. There has been no unplanned downtime in FY19. Mr. Nicastro requested that he be included on scheduled downtime notices so that he may begin to track that information.

Secretarial Report

- Ms. Beatty reviewed the FY19 budget report. She indicated that income tax check-off revenue is down due to an update to the Department of Revenue’s (DOR) processing system; however, a May deposit was made that is not reflected on the report. Ms. Beatty noted that the cost of personal services is down due to the SOSA vacancy and that there will be additional large expenses in the “Other (Materials, Initiatives, Media, etc.)” line item in June for the Donate Life Month media campaigns. She also reported that the State Data Center charges are from April 2018 through February 2019 only; March should pay out this year, but April through June will likely be charged in FY20. She also explained the “Administrative & Network Costs” line item that is unavailable to the Program. Ms. Beatty added this line item so that the report figures match the fund balance figures obtained through the State Treasurer’s Office and reported by Mr. Nicastro. All other expenses were either less than or on target with what the Program expected. Ms. Beatty explained that year two of the DMV Education Grant awarded to Mid-America Transplant will end on September 15th and that any funds remaining in the FY19 budget will roll over to FY20 to finish out the remaining three months of year two. Ms. Kellen indicated that Mid-America Transplant is working on the grant’s year three budget and will submit it to the Program next week. Ms. Beatty explained that a refund line is included in the budget in case an individual wants a refund of their contribution. Ms. Simaitis requested the total number of “Be An Organ Donor” license plates issued to date; the Committee asked Ms. Wisch to report that information at the next meeting.

Action Items:	Person Responsible:	Deadline:
Contact Boards and Commissions Office and local legislators about appointments to Committee	Individuals who have applied for GODAC positions	Until appointments made ASAP
Add Mr. Nicastro to downtime notice listing	Valerie Volkart	Report at next meeting
Pull number of “Be An Organ Donor” license plates issued to date	Gina Wisch	

Unfinished Business

Strategic Planning

- Brown Smith Wallace staff, Bret Simmons and Ron Steinkamp, provided a presentation of the newly drafted strategic plan. The presentation included an overview of the research conducted by the agency, the planning process and plan development. Mr. Simmons and Mr. Steinkamp also reviewed the plan goals and objectives. Concerns expressed about the strategic plan goals and objectives included:
 - Mr. Lee had issue with the use of the term “excellent” when referring to Missouri’s designation rates, as it may imply that we are satisfied with the current rate of 50%; Ms. Finn agreed. Mr. Lee suggested changing the statement to “positive trend in registration.”
 - Mr. Lee also expressed concerns regarding the plan’s potential reliance on partner support and partner progress reporting. Since the Program only has two staff, it appears a lot of support from partners will be necessary to carry out the plan. The OPOs already report to 15 regulatory bodies and Mr. Lee is unsure whether partner reporting is something they can or want to do. Mr. Nicastro suggested that revisions to the partner reporting and partner agreement language be considered.
 - Mr. Lee would like clarification on the scope of the proposed partner agreement and what it entails, as that will impact how Mid-America Transplant can support the plan.
 - Mr. Nicastro indicated that the plan speaks more to the Program and what they will do rather than GODAC. He noted that the plan does not engage Committee members or partners and minimizes the Committee’s impact and role.
 - Mr. Lee would like to know what joint messaging will look like. The registry message is going to be an issue due to multiple partners’ support of the National Registry over the State Registry.
 - Mr. Nicastro would like to see independent goals and objectives that speak to GODAC specifically and what they should do and how they want to advise the Department, Program, Governor and General Assembly. He would like the sub-committee to revisit the plan and include goals and objectives for GODAC.
 - Ms. Simaitis requested additional time to review the plan prior to voting on the plan’s approval/adoption.
- Mr. Duncan moved to table the plan at this time. Motion carried. Four voted in favor, one abstained. A motion will need to be made and carried at a future meeting in order to place the strategic plan back on the agenda.
- Ms. Keiser requested Committee members and partners review the plan and provide feedback/suggested changes to the Program by July 19th.

High School Education Project

- Ms. Harbur reported that the Learn Life Savers website is live and can be accessed at [learnlifesavers .org](http://learnlifesavers.org), [.com](http://learnlifesavers.com), [.net](http://learnlifesavers.net) or [.info](http://learnlifesavers.info). The sub-committee is currently working on a plan to present to school boards as allowed by HB 2129. The state will be broken into 17 regions and a “star volunteer” will be assigned to conduct presentations in their assigned region. The presentation plan is expected to take about four years to reach the 525 Missouri school boards. All volunteers will utilize the same PowerPoint presentation so that everyone is saying the same thing. Gift of Life will be presenting Learn Life Savers at multiple school-related association conferences. Fourteen teachers statewide are currently testing the site navigation; feedback is due to Ms. Harbur by July 1st.

2019 Capitol Day and Donor Family Recognition Summary

- Ms. Volkart reported that the April 9th event went well with 183 attendees recorded during check-in and 73 donors celebrated. The planning team was able to secure a dedicated parking lot for attendees courtesy of the City of Jefferson and a shuttle provided by Mid-America Transplant. It was reported that some of the Committee members did not receive information about the parking lot and shuttle; Ms. Volkart will ensure that all information for the 2020 event is distributed to Committee members and partners. Surveys were distributed at the event and 27 responses were received. The majority of survey respondents felt the event overall was excellent or very good. Ms. Volkart shared some of the comments and concerns submitted by attendees. She

will send the full survey report to the group. The 2020 Capitol Day and Donor Family Recognition event will be held on Tuesday, April 14th.

2019 Proclamation

- Copies of the 2019 Donate Life Month Proclamation are available. Contact Joan Keiser.

Sharp Media Group Data Report

- Mr. Lee reported that MAT saw slight increases of about .1 or .2 percent in donor designation rates, but they eventually went back down. The contract was not renewed. MAT reallocated the Sharp Media Group contract funds to minority education outreach.

Online Registrations

- Mr. Nicastro reported that out of the 3,879,574 million records in the registry, 9,505 registered online and 9,896 registered through the paper application process. Ms. Beatty explained that the custom report Mr. Nicastro referenced is as of the current date and that registrants are counted once and the registration source is based on the most current registration. Mr. Nicastro was surprised that online registration is the least used method of enrollment. He would like to have a report of the number of hits to the sign up page of the website. Ms. Beatty will find out if the information is available. Mr. Nicastro suggests a more condensed informed consent component for online registration in the new system; a simpler, less time-consuming process might increase online registrations.

Walgreens & Donate Life ECHO Project

- Ms. Finn had to leave for another meeting and was not available to report.

Department of Conservation Update

- Mr. Lee reported that MAT received a request from Department of Conservation to renew the MOU. There was an issue early in the year with the shortened link not being honored by Google, which caused a slight drop in utilization in February and March. Since updating the link, clicks are around 881. There were approximately 5,000 total clicks in 2018. There is no charge for the partnership, so Mr. Lee recommends we continue to renew the MOU. Ms. Beatty reported that the DHSS Director wrote a letter of support to the Department of Conservation Director requesting the MOU continue. Conservation prefers to continue the partnership through an MOU and not legislative action.

Action Items:	Person Responsible:	Deadline:
Review strategic plan and provide suggestions	Committee Members and Partners	July 19, 2019
Send Donor Family Recognition survey report to group	Valerie Volkart	Earliest possible
Inquire about adding the number of hits to the sign up page to the web analytics report	Virginia Beatty	Report findings at the next meeting

New Business

Legislative Update

- Ms. Hentges reviewed passed 2019 legislation that may affect the Program. The information included in the update was shared with the group prior to the meeting.

FY20 Proposed Budget

- Ms. Beatty reviewed the proposed FY20 budget. Multiple Committee members and partners expressed concern with the proposed budget, especially the projected cost of the registry modernization. Committee members would like for Ms. Beatty to amend the budget to include:
 - A more detailed breakdown of the “Other (Materials, Initiatives, Media, etc.)” line item;
 - An indication of the costs associated with the donor symbol sticker and the registry modernization; and
 - The addition of a symbol to indicate an increase or decrease for each line item.

Mr. Nicastro moved to postpone the FY20 proposed budget approval. Motion carried. Four voted in favor, one abstained. Ms. Keiser recommended a special meeting be held to address the FY20 budget. Ms. Beatty will amend the budget and schedule a special webinar meeting in July.

2019 Missouri State Fair

- Mr. Duncan reported that the 2019 State Fair is scheduled for August 8th through 18th. He has not done anything in relation to the State Fair. He stated he will be returning the Donate Life Globe parade float to its creators and no longer haul it around the state.

Driver License Renewal Notice

- Ms. Simaitis shared a copy of the DOR driver license renewal notice with the group. Tammy Kliethermes, who works for the House of Representatives, suggested to Ms. Simaitis that something about the organ donor questions be included on the renewal notice so that individuals are able to inform themselves, talk with family and be prepared to answer the questions. Ms. Simaitis requested that DOR add information about the questions to the notice. Mr. Nicastro offered to come up with suggested language to provide to DOR through the SBAR process. Ms. Wisch reminded the Committee that the primary purpose of the card is to ensure that individuals have the proper documentation when they arrive at a license office to renew. DOR is willing to review suggested language; however, the group needs to be mindful of DOR's other priorities, space limitations and that there are additional donation questions; DOR cannot appear to give special treatment to one group over the others. The renewal card is reviewed about every six months. Ms. Wisch indicated that some of the larger license offices are now using a pre application that individuals complete while they are waiting. The pre application does include the donor questions. Ms. Simaitis also suggested that DOR add the dollar donation to the boater registration. Ms. Wisch indicated that the statute may not mandate the offices to ask during boater registration.

Action Items:	Person Responsible:	Deadline:
Revise budget documents	Virginia Beatty	Prior to special meeting
Send link to registry modernization RFP to the group	Valerie Volkart	ASAP
Work on language for the license renewal notice	Peter Nicastro	Have available for review at next meeting
Find out if statute only requires the dollar donation question to be asked during vehicle registration	Virginia Beatty	ASAP
Discuss possible legislation to add dollar donation to boater registration	Committee Members	Next meeting

Partner Updates

Mid-America Transplant (MAT)/Team Missouri

- MAT had a great Donate Life Month. They continued their green-up games partnership with Missouri State University and Southeast Missouri State University for the second year. Attendance was anywhere from 300 people at a softball game to 6,000 people at the Bears vs Tigers baseball game. The green-up games agreement is for three years and will continue to be evaluated for impact moving forward. Candlelight memorials were held in Springfield and St. Louis, both of which were very well attended. The MAT 5K will be in October. They will be doing an ECHO (Every Community Has Opportunity) event in partnership with Walgreens at six different sites on July 26th. Anyone who would like to receive the MAT Impact Report should let Mr. Lee know and he will add him or her to the mailing list. MAT has done well over 200 Paths of Honor; they are working to incorporate the Donate Life flag. Please reach out to Mr. Lee with any ideas on ways to improve the donor family experience. St. Louis University and Barnes Jewish Hospital are both working toward HOPE Act approval. Barnes is also working to approve a policy regarding hepatitis C positive organs. MAT is currently working with Vector Communications to ensure their messaging is in touch with the African American community and identify areas for improvement. Ms. Beatty informed Mr. Lee about an individual from St. Louis who requested a removal form because her transplant team indicated that she could not be a donor due to her antirejection medications – this may be an opportunity for additional education among transplant centers in the area. MAT has expanded their criteria for donation after cardiac death (DCD) to evaluate donors for DCD up to 65 years of age.

Midwest Transplant Network (MTN)

- Ms. Finn had to leave for another meeting and was not available to report.

Saving Sight

- Mr. Kovacs reported that Saving Sight collaborated with both OPO partners on Donate Life Month activities. Saving Sight is concentrating on having a large presence in their hospitals and is actively working with coroners in Jackson, Greene and Boone counties to continue fostering those relationships. They had approximately 2,500 donors in FY19.

Missouri Kidney Program (MOKP)

- Ms. Hardesty reported that MOKP is currently working on education initiatives including a Kidney Echo through Missouri Telehealth Network, as well as initiative to educate social workers on the resources provided by MOKP. They are also offering a series of webinars geared toward nursing staff, FQHCs, and other individuals who see patients before they are in end stage renal disease and placed on dialysis. MOKP is collaborating with the state Program on a transplant project to develop materials for kidney/dialysis patients to keep them on track and introduce them to the option of transplant through living donation.

Gift of Life (GOL)

- Ms. Harbur reported that the Life Savers classroom program school year finishes at the end of July; while the final data is not available, she feels they are close to 700 classroom presentations and 30,000 individuals reached. They are revamping the Life Savers look – changing design of materials and photos. GOL is hosting a speakers training on August 6th from 5:00 to 7:30 pm. The Life Savers Rally will be held on September 23rd at Rockhurst High School. GOL is working to secure funding to hire a part-time educator to speak in schools in communities of color within the Kansas City area. GOL is collaborating with MAT to bring the Life Savers classroom program to St. Louis. The recruitment process for a part-time educator in the St. Louis area will begin at the end of June; the goal is to have an individual hired by August and trained by the end of September. Since 2010, the GOL Mentoring program has served 675 families from 26 states.

Department of Revenue (DOR)

- Ms. Wisch reported that since the March 25th implementation of Real ID, DOR has issued 332,229 documents of which approximately 68,000 were Real IDs. DOR has not experienced the level of Real ID requests outside of an individual’s renewal period that they had anticipated; they are seeing about 15% to 20% on a daily rate that are outside of the renewal period. This may increase over the next year. DOR included organ donor information on the Real ID renewal notice and Real ID posters that were distributed to license offices and state airports. The information is also on the digital displays in the DOR central office and other license offices that have digital display capability. Additional Real ID information pushes will be implemented over the next year. DOR is also working with their vendor to redesign the license to incorporate the donor sticker.

Department of Elementary and Secondary Education (DESE)

- Ms. Beckman is now the Director of Missouri Healthy Schools and currently has two grants that she oversees. Her program is working with DHSS and the Centers for Disease Control and Prevention (CDC) to complete an evaluation of chronic disease risk factors that may result in health barriers to student learning. Research shows that if these risk factors are reduced, the student’s academic achievement is increased. Ms. Beckman’s program just finished the Youth Risk Behavior survey, which will be used by CDC to generate updated figures for risk behaviors among Missouri youth. CDC selected Missouri as one of the top three states for the evaluation project. Ms. Beckman is willing to aid the high school education sub-committee in getting into school-related conferences as vendors and presenters. She does recommend that the group consider alternative methods of communication (i.e., webinars, Echo, etc.) to provide general public education and awareness. The Committee may also want to try to get information into school health clinics, which are becoming more common among Missouri schools.

Next Meeting**Agenda/Logistics**

Send out polls to determine date of the special meeting and the next full meeting Virginia Beatty

Adjourn

Meeting adjourned at 3:25 p.m. Joan Keiser, Chair

Approved as Amended at 9.17.2019 Meeting.