



Governor’s Organ Donation Advisory Committee Minutes

DATE 7.21.2021 | Runge Nature Center & WebEx Meeting ID 177 748 7752



Note taker (s):	Vicky White and Benjamin Pringer
Voting Members:	Deb Simaitis, Peter Nicastro, Jan Finn, Phil Duncan, Virginia Beatty
Partners/Guests:	Jake Buxton, Michelle Shanahan DeMoss, Kim Harbur, Laurie Hines, Lori Kramer-Clark, Kenny Kovacs, Kevin Lee, Chelsea Richardson, San Simaitis, Michala Stoker, Shelly Wehmeyer
DHSS Staff:	Rachel Allen, Daniel Bogle, Steve Cramer, Benjamin Pringer, Vicky White
Called to order:	Vice-Chair Deb Simaitis called the meeting to order at 9:01 a.m. and announced a quorum.

Welcome, Introductions, Agenda Approval and Minute Approval

Mr. Buxton was recognized for arranging the use of the Fish and Wildlife room at the Runge Nature Center. Members and guests introduced themselves; Ms. Michelle DeMoss (Donor Mom), Lori Kramer-Clark (MTN), Kevin Lee (MAT), and Chelsea Richardson (Transplant Coordinator). Agenda was approved as amended. December 1 and 21, and February 24 minutes were approved as edited.

Conclusion: Informational

Action Items:	Person Responsible:	Deadline:
Introductions, agenda approval, and minute approval	Committee members and partners	Ongoing

Reporting of Officers/Committees

Chairperson Report (Ms. Simaitis/Ms. Beatty)

- Committee Appointments. Governor Parson is considering nominating more members to the committee. Applicants should reach out to their Senator. Appointments may be made as early as July 26. Applicants can direct questions to the Boards and Commissions office at (573) 751-3222. There are currently five vacancies and five members serving on expired terms.

Comments/Thoughts (Ms. Simaitis)

- Committee thanked for its dedication to Organ and Tissue Donation and expressed the honor it is to work with this group.

Dashboard and Financial Trend Updates (Mr. Nicastro)

- Donor Fund Cash Flow Table and Balance Graph. The fund has a balance of 2.44 times the trailing 12-month expense. The target is not to exceed three.
- Dashboard
 - The contribution rate, originally set at five percent, has not changed in four to five years. Yet, over the past fourth quarter, April through June 2021, the rate was at twelve percent. Possible reasons include 1) extension of Real ID Act from October 2021 to May 2023, 2) people catching up on driver license renewals, 3) others getting a Real ID (even if it’s not their renewal time), and 4) DMV offices asking the question more consistently. The number of people consenting per day increased from 346 in March 2021 to 397 in July 2021.
 - Youth Enrollment (16 & 17 year olds). Based on estimated census data, youth enrollment is approximately 60 percent of the target population. Mr. Kevin Lee suggests the committee look at trend lines of enrollment and birth rates because across the country there will be a dip in high school and college enrollments over the next 10-20 years. He further suggests looking at overall youth enrollment against Missouri’s population trend. Mr. Lee also noted that it would be interesting to trend youth data against overall potential referrals for Organ and Tissue (especially tissue) donation that are on the registry as a historical trend for the State of Missouri. Mr. Nicastro to contact Mr. Lee, Ms. Lori Kramer-Clark, and Mr. Kovacs about attaining data.
 - The Donate Life Missouri Facebook page. Not much support. Mr. Lee reports that with the outsourcing of their marketing department they do some automated feeds to the Donate Life Missouri page. Ms. Stoker’s opinion it that it is redundant to have the Donate Life Missouri Facebook page without knowing the goal of that page and understanding the page’s history. Ms. Simaitis placed the final decision with Mr. Nicastro about a Social Media metric on the Dashboard.

SWOT/SSC Results Data Discussion (Mr. Nicastro & Committee)

- Many diverse responses to the SWOT (strengths, weaknesses, opportunities, threats) or SSC (start, stop, continue) analysis. Mr. Nicastro discarded the Departments input. He categorized the other responses into four areas, strengths, weaknesses, opportunities, and threats. Future conversations around these four areas can guide team goals. Ms. Simaitis will add the topic as an ongoing agenda item.
- Potential Threat-human trafficking and organ trafficking on the black market. It is illegal in the U.S. Article comments indicate people are removing themselves from registries as they are fearful their organs might be shipped somewhere else. Ms. Simaitis asked if MTN, MAT or Saving Sight has seen this as an issue. Ms. Kramer-Clark responded that in her interactions she hears college students do not want to register because they are afraid the hospital will not take care of them. Mr. Lee reports he has heard more frustration from transplant nephrologists who have had high net worth clients go to Southeast Asia, purchase a kidney, then come back and want care here because they had terrible care and are in bad physical condition. He also commented that diversity in resources keeps people from becoming donors. The perception in the southern part of the state is that all of the organs go to St. Louis or Kansas City and that the southern part of the state is kept intentionally poor. Another misconception is that a lot of organs donated from African Americans go to white recipients. No indication human or organ trafficking is a concern as it relates to organ, eye and tissue donation in Missouri.

Secretarial Report (Ms. Beatty)

- The FY21 financial report presented in final draft and waiting on balance corroboration.
 - Publishing the FY20 annual report online saved about \$3,000 in printing cost in addition to mailing costs. Mr. Duncan asked for a hard copy of the annual report and Mr. Pringer said he would mail it to him.
 - Travel was minimal. The Annual Donate Life America Meeting was virtual and a reasonable registration fee, so Ms. Allen and Ms. Beatty attended.
 - Concern about the fund balance and targeting of funds by other departments discussed.
- Revenue projections based on a five-year average from 2017 through 2021. The projected revenue is \$306,000. Ms. Kramer-Clark suggested printing a limited number of annual reports and distribute where they will have the most impact; rural America. Mr. Lee concurs.
- The program updated the DOR info card and cost accounted for in the budget line item.
- Money is budgeted for social media ads and spending will depend on fund balance and staff availability.
- Dollars set aside for any needed and wanted registry changes.
- Funds prohibited for the Donor Family Recognition Program use based on current law review.

Conclusions: Informational & Actionable

Action Items:	Person Responsible:	Deadline:
Contact Senator & Boards and Commissions Office	Committee Applicants	Ongoing until positons filled
Donate Life Missouri Social Media Data & Dashboard	Mr. Nicastro	Ongoing
Current Census Data to Mr. Nicastro	Ms. Beatty	As schedule permits

Partner Updates

Mid-America Transplant (MAT)/Team Missouri (Mr. Lee)

- Fiscal year is a calendar year and reports indicate consistent numbers of organ donors compared to the same time last year. MAT expanded clinical criteria and in 2020, they approached 492 families for organ donation and 354 said yes. Two hundred seventy-eight of the 354 converted to being organ donors resulting in 815 lifesaving transplants.
- The most pressing challenge is organ placement; lungs and the change in national kidney allocation. Mr. Lee provides the following historical perspective for the committee, partners and guests. For many years, 80 percent of the organs MAT recovered stayed in the St. Louis area, then it slipped to 70, then in 2019, it dropped to 60 percent. In 2020, 408 recovered organs went out of the service area and 407 recovered organs transplanted in the St. Louis area, putting the percentage of recovered organs remaining local at about 50 percent. For 2021, MAT projects 80 percent of recovered organs will leave the community. As an example, one kidney recently sent to SSM St. Louis University Hospital and 23 to Methodist in Memphis, TN. The change in allocation creates equity for those people are living in communities served by under-performing organ procurement organizations.
- COVID is a rule out for organ tissue potential. There is no documented evidence at this time that a kidney transplant transfers COVID19.
- Employees will be returning to their previous positions. A small group of volunteers has returned and is working in the boardroom as long as they are masked.
- Work continues on the new Family House with an anticipated completion date of Donate Life Month (April) 2022. When completed, the house will have 21 apartments in a freestanding three-story building. There will be six one-

bedroom and 15 2 bedroom apartments for families from across the region who are waiting or recovering from lifesaving gifts. It is nestled between I44 and I64/40 in close proximity to transplant hospitals.

Midwest Transplant Network (MTN) Refer to Addendum 1 for full report. (Ms. Kramer-Clark and Ms. Stoker)

- Data report for January through June 2021: 164 organ donors annualizes to 328. MTN's transplant volume for 2021 is 439 for the first six months and annualizes to 878. Sixty-five percent of those were first person authorized. Tissue volume for the same period is 895, which annualizes to around 1,800.
- Donor Care Unit seven bed ICU is under construction and will have operating rooms. Anticipate completion date is the 2021 holiday season and opening in the spring.
- Focus areas for 2021 are:
 - Building internal strategies and initiatives toward the AOPO initiative, 50,000 transplants by 2026.
 - Hospital engagement.
 - Annual critical care symposium. Event typically occurs in October in Arrowhead.
 - Kansas City Royals and Chiefs yearbook advertising, including a QR code with the Chiefs ad that will take a person directly to the ShareLifeMidwest.com site so they can add their name to the Missouri or Kansas registry.
 - Partnering with Kemper Museum of Contemporary Art on July 29 to host a donation panel discussion. The panel, moderated by one of our family service coordinators, will consist of a heart recipient, a living kidney donor, a donor mom, and a trauma surgeon.
 - Together We Save More Lives campaign for National Multi-Cultural Awareness month. This year we will be displaying the Faces of Donation and sharing three donor hero stories from the service area. Ads will appear on community busses, on select gas toppers, and two local radio stations. Each ad will contain a unique QR code that will take people to the registry and allow us to track those visits.
 - Organ Donation Day at Kauffman Stadium on August 17; working with the Kansas City Royals to sponsor the event.
 - September is National DMV appreciation month. Celebration of partners will be shared at the next meeting.
 - The 2022 Rose Parade float honoree, Christopher Hutson Jr., was an organ and tissue donor in May 2017.

Missouri Kidney Program (MoKP) (Ms. Hines)

- The 2020 data points to a 50 percent increase in deaths in MoKP's patient population. Kidney disease is the leading risk factor for severe COVID-19 infections and one of the top leading causes of COVID-19 deaths.
- Dialysis centers now have a quality metric that requires a certain percentage of people in their centers listed for transplant.
- The hard work that Ms. Virginia Beatty and Ms. Laurie Hines did on the My Transplant Ready Workbook has really been helpful. Ten additional workbooks sent to each dialysis center in the state.
- MoKP is starting its third year of the kidney disease ECHO. Having transplant staff on the ECHO allows discussion about all stages of chronic kidney disease (CKD) through end stage and transplant for primary care providers who are the target audience for ECHOs; particularly in rural Missouri.
- MoKP is seeing an increase in demand for transplant assistance (up to \$1,000 to either kidney donors or recipients). MoKP is considering shifting some money to pre-transplant assistance as dialysis centers report people are having a hard time getting to their transplant evaluations.
- Ms. Beatty serves on the workgroup rethinking financial assistance distribution and tackling other issues like immunosuppressant drug coverage. Medicare will extend immunosuppressant coverage through 2023 and kidney transplant recipients will have coverage for life.
- Ms. Sandy Hentges recognized for her forward thinking leadership in partnering with the National Kidney Foundation. MoKP will be the first to partner with the DHSS pm this one-to-two year initiative targeting prevention and early stage CDK.

Gift of Life (GOL) Refer to Addendum 2 for full report. (Ms. Harbur)

- Exceeded the Life Savers program goal by facilitating 376 presentations, 239 virtually and 125 in person. The recorded high school program presentation is on the GOL website, and the link shared with teachers.
 - A two-day program reassessment occurred and there will be updates to the program.
 - On August 2, seven teachers will participate in a two-hour round table to discuss differences between in-person and virtual course to improve the online program.
- Executive Director Ms. Julie Klima and Ms. Harbur will be networking in St. Louis in an effort to gain access to high schools.
- The Life Savers Rally at Rockhurst High School will be in February 2022 rather than in the fall 2021.
- The Transplant Mentors program went national and is now servicing 40 hospitals coast to coast.

- Transplant Talks hosted four times a year includes different topics for recipients and the mentoring program. Dr. Macy Levan, JD, PhD, Johns Hopkins University, will present at the August 5 talk at 7 pm on the effects of COVID-19 among the transplant community.
- The sold-out golf tournament is October 1.
- Journey mapping for programs and special events is coming to completion.
- The “Give to Live” campaign exceeded goal of \$180,000 by raising \$220,000.
- The “GoSeeDo” will be May 7, 2022.
- Learn Life Savers (online high school education program)
 - Seven captains are scheduling and presenting school board presentations. Captains will meet at the end of July via Zoom and then an in-person meeting in Columbia on August 16.
 - Website redesign is occurring in order to make the site more teacher friendly. A student lesson added in March 2020 and is part of the teacher’s lesson plan.
 - Ms. Simaitis’ will share the link with a Lincoln High School counselor who had not heard about the program.

Department of Revenue (DOR) (Ms. Wisch)

- The Real ID compliance extended to May 3, 2023. Discussion about the change and informational tools held.
- Senate Bill 258 passed allowing a collection of optional donation to the Medal of Honor Recipients Fund. This may affect the total organ donation collections. DOR will be implementing this on the motor vehicle side only.
- The audit team continues to evaluate license offices during compliance reviews and includes ensuring they are asking all mandatory organ donation questions. Offices may be subject to damages if requirements are unmet.

Department of Conservation (Mr. Buxton)

- Permit sales are up and interaction with the public online portal that connects to the Donate Life Missouri registry is increasing. Ms. Simaitis noted MDC website’s “Click Here to Save a Life”. Very powerful.

Department of Elementary & Secondary Education (DESE) (Ms. Wehmeyer)

- HOSA going well. Numbers are great and we are moving back to in-person events. The fall conference will be at Steven’s College in Columbia, Mo. September will be the Washington Leadership Academy.

Saving Sight (Mr. Kovacs)

- Partnership with the Kansas Eye Bank established and expected to expand eye and corneal transplants. A new Fellow will conduct corneal transplants in the Wichita area, replacing the previous doctor who retired.
- Saving Sight recovered over 6,400 pieces of tissue for transplantation or research during the fiscal year that ended June 30, 2021. Direct transplants changed 3,115 lives.

Conclusions: Informational

Action Items:	Person Responsible:	Deadline:
Updates	Partners	Ongoing
Ask Motor Vehicle Division about Specialty Plate Promotion & Plate Comparison Data	Ms. Wisch	Next meeting.

Unfinished Business

2021 Donor Family Recognition (DFR) Update (Ms. Allen)

- Virtual event. Creation of a YouTube video had guest speakers, including Governor Parson, donor recipients, and donor families. In addition, a donor recognition with the names and photos of donors. As of July 21, 2021, the video has over 1,200 views. The packet included a coloring book and colors donated by Camryn Crist-Ms. Route 66, adult coloring pages, Donor Family pins donated by Deb and San Simaitis, and Redbud tree seeds donated by the Missouri Department of Conservation. While families wished for an in-person event, they understood the why behind a virtual event. Positive feedback received on the speakers and their stories, donor names and photos, and getting the tree seeds to plant in honor of their loved one.
- The first planning meeting for the 2022 event will be in early August. Plans for the April 12, 2022 event will be for an in-person program with a virtual component. Status of COVID-19 will determine the event’s outcome.

2021 Legislative Session Update (Mr. Bogle)

- Committee praised because while serving on expired terms and multiple vacancies, members continue to press on and make actionable steps that have made a huge difference to the program.
 - HB 431 (Right to Sepulcher). While the bill did not pass, Mr. Bogle expects to see it again in the future.
 - HB 585 (Next-Of-Kin and Final Disposition of a Deceased Person’s Remains). The bill lists the order of priority for who can control the disposition of a dead human body. It contains language that a surviving spouse will not have priority if an action of dissolution of marriage is filed and pending in a court. The next-of-kin of a deceased person may delegate the final disposition to an agent through a power of attorney. This bill conflicts with current laws that govern organ donation (Anatomical Gift Act). The bill would allow for

whoever has priority to delegate their ability to someone else. This may cause a conflict. It was determined that the Department should connect with legal counsel of MAT and MTN to discuss the bill further prior to any possible pre-filing in December.

- o End of Life Homes may create an opportunity to speak with another group about the gift of organ donation.

Conclusions: Informational & Actionable

Action Items:	Person Responsible:	Deadline:
Monitoring legislation and feedback	DHSS and Committee Members	Ongoing
Donor Family Recognition Program	DHSS and Planning Team	Ongoing

New Business

Election of Chairperson (Ms. Simaitis)

- Committee polled about postponing the election until the next meeting. Consensus was to wait.

Specialty Plate (Ms. Simaitis)

- o Impact. Plate generates conversation during travel. Ms. Simaitis inquired if the OPOs inform families about the plate's availability. Ms. Clark and Mr. Lee both shared that there was so much discussed with the family at the time of death that they do not. Consideration for inclusion in a subsequent mailing is possible.
- o Ms. Simaitis inquired about the possibility to assist families with the emblem use fee for the first year. Ms. Beatty will check with DOR.

2022 Legislative Session (Mr. Bogle)

- Expect reintroduction of bills in the 2022 legislative session based on activity during the 2021 legislative session.
- Department Proposals. Current law restricts how the program can spend funds and with whom to contract. The program is looking to improve fund flexibility. The process: division combines all proposals, submits them to department leadership, and leadership determines and which proposals go to the Governor's office for consideration. The Governor's office authorizes the proposals they want to make part of their agenda.

Conclusions: Informational & Actionable

Action Items:	Person Responsible:	Deadline:
Elections	Committee	Next meeting.
Specialty Plate	Ms. Beatty & DOR	Next meeting.
Report 2022 Legislative Session Insights/Updates	Bogle, Committee & Partners	Ongoing During Session

Good of the Order

Closing Comments/Thoughts

- Ms. Simaitis provided a breakdown of membership: four: organ procurement organizations positions; four organ recipients, families of organ recipients, organ donors, and families of organ donors positions; one hospital position; and one department position. The term is five years and appointees serve at the pleasure of the Governor.
- Ms. Beatty thanked Ben for supporting the program over the last year and a half wishing him well in his new position. She also announced Ms. Allen will be on maternity leave and wished her well.
- The next meeting will be in September or October. Ms. Beatty will poll for a date.

Conclusions: Informational

Action Items:	Person Responsible:	Deadline:
Closing Comments and Thoughts	Attendees	Ongoing

Next meeting.

Agenda/Logistics (September/October 2021)

- Submit meeting preference, agenda items, etc. for the next meeting.

Conclusions: Informational & Actionable

Action Items:	Person Responsible:	Deadline:
Submit agenda items	Committee	Prior to next meeting
Develop agenda.	Ms. Simaitis & Ms. Beatty	Prior to next meeting
Issue meeting poll.	Ms. Beatty	As schedule permits.
Send out agenda and handouts.	Ms. Beatty	Prior to next meeting.

Adjourn

Meeting adjourned at 3:16 p.m.	Deb Simaitis, Vice Chairperson
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Approved as Amended 9.24.2021