



Governor’s Organ Donation Advisory Committee Minutes

DATE 2.28.2022 | WebEx Meeting ID 2455 440 1368



- Note Taker (s):** Virginia Beatty
- Members:** Deb Simaitis, Peter Nicastro, Mary Ann Burns, Kevin Lee, Lori Clark, Kenny Kovacs, and Virginia Beatty
- Absentees Members:** Jan Finn
- Partners/Guests:** Gina Wisch, Tammy Turner, Kim Harbur, Unidentified Guest
- DHSS Staff:** Steve Cramer, Sandy Hentges, Ian Collins
- Called to order:** Vice-Chairperson Deb Simaitis called the meeting to order at 9:08 a.m. Quorum present.

WELCOME/APPROVALS (Introductions, Agenda Approval and Minute Approval)

Introductions made including Ian Collins new staff of the Missouri Organ and Tissue Donor Program. Agenda approved as presented. September 24, 2021 minutes approved with edit; correct spelling of Ms. Harbur’s name. November 23, 2021 minutes approved as presented.

Conclusion: Informational & Actionable

Action Items:	Person Responsible:	Deadline:
All meeting action items are outlined in Addendum 1	Members and Partners	Ongoing

OFFICERS/COMMITTEES

Appointments and Confirmations (Ms. Simaitis)

- Members confirmed by the Senate; Mary Ann Burns and Kevin Lee (January 2022), and Lori Clark and Kenny Kovacs (February 2022)
- Mr. Phil Duncan’s resignation letter read, his service recognized, and a plaque presentation planned for the May 2022 meeting. The committee accepted Mr. Duncan’s resignation
- Annual documents completed
- Annual training is available; functionality of the survey to be addressed later in the year

Dashboard and Financial Trend Updates (Mr. Nicastro)

- Donor Fund Cash Flow: The fund has a balance of 2.59 years of trailing 12-month expense
- Dashboard:
 - The contribution rate for the period September through November 2021 is at 10.67%
 - Events lagging due to the pandemic.
 - Enrollment numbers reflect approximately 383 new enrollments per day (≥ 18)
 - Youth Enrollment (< 18) is 95,339 or 62.2 percent. Once this population turns 18 years of age, they move to the adult population statistic
 - Changes to social media are still under consideration
 - Unscheduled registry down time is at 0 hours

Secretarial Report (Ms. Beatty)

- Financial: Revenues are higher than anticipated. Annual report print costs will be approximately \$3,400.
- Annual Report: The report is available at www.DonateLifeMissouri.org, under “Other/Publications.” The Missouri legislature and the Governor’s office received the report link in January. Distribution of printed copies will be in late April or early May
- Box Site: Members requested Box access instructions

Conclusions: Informational & Actionable

PARTNER UPDATES

Partner updates given during the meeting are provided as Addendum 2

Conclusions: Informational & Actionable

UNFINISHED BUSINESS

High School Education Project (Ms. Harbur)

- Refer to partner report above.

SWOT/SSC* (Ms. Simaitis)

- As a standing agenda item, it is a time to share ideas or brainstorm a topic/issue. The *Donor Family Recognition Program* and *Learn Life Savers* both started here
 - **Driver License and Heart Symbol vs. Registry:** Ms. Clark indicated the two questions asked during driver license application is hindering authorization at time of death because some families focus on the registry and license documents not matching. It conveys the procurement organization does not have their act together, even after explaining their loved one had the option to have the symbol on the license. Ms. Clark asks the committee to think about it. Kansas just changed from two questions to one; it will be a couple of years before a full renewal cycle occurs and change effectiveness analyzed. Refer to Addendum 3 for summary.
 - **Threats:** Refer to new business

Conclusions: Informational & Actionable

NEW BUSINESS

Election of Officers (Committee Members)

- Postponed until the May 2022 meeting. The Bylaws indicate, "Other officers shall be elected by roll call at the regular meeting immediately following April 1 of each even calendar year." Past chair suggested written procedures outside of Bylaws, the Committee may want to consider this suggestion
- Committee Membership. Eight members currently serve. The hospital representative and donor/recipient family positions remain open. Four of the eight members received Senate confirmation in January and February 2022
- Mr. Lee requested the hospital representative position be on the May meeting agenda

2022 Legislative Update

- HB 1861 filed by Representative Eggleston
 - Includes COVID-19 vaccination status and organ donation
 - A House perfected version of this bill has provisions that a person cannot be denied a transplant because they have not been vaccinated for COVID-19. Proposed language results from four nationally publicized incidents of individuals denied a transplant due to no COVID-19 vaccination; none of which are from Missouri
 - Vaccination is a transplant issue. MAT has referred bill information to the Government Relations teams at Barnes Jewish, SSM Health, and to the Missouri Hospital Association
 - The Governor's office has not taken a position and asked the department for feedback. The recommendation was to consult with the transplant physicians and hospitals that determine transplant policies
- SB 1146 and HB 2680
 - Proposal filed in both the House and Senate, are not identical to the initial proposal, and currently not in committee. The Senate sponsor is Barbara Washington (D) and the House sponsor is Dave Griffith (R)
 - The Department communicated the committee's strong concerns to the Governor's Office. Bill amendments can occur throughout the process. As Missourians, you can express your opinions publicly

Threat-Donation Age (Ms. Simaitis)

- Age policies are a threat, and shared her personal experience when her husband, San, died on Friday, January 21, 2022. Refer to Addendum 4 for discussion summary and questions for the committee to explore and answer

Threat-Reasons for Removal (Ms. Beatty)

- **Removal Data:** The program is working with the vendor to develop a removal report. Preliminary data indicate that over 150 removals relate to family experience and about the same number citing spiritual/religious reasons
- **COVID-19:** The program is receiving calls (and an email) related to COVID-19; if vaccination is required to be a donor or the person has to be vaccinated to receive a transplant, they want their name removed from the registry
 - It is unknown if Missouri transplant centers require the COVID-19 vaccine for listing. Medical requirements vary across the region, transplant center, and organ type. Listing requirements can be extensive and there are no standards
 - MTN's team is not speculating on any transplant center; they inquired of a local transplant center about listing requirements and the response was "complex." MTN is also receiving posts and emails about the COVID-19 vaccine asking to be delisted
 - MTN and MAT have not experienced potential donor families refusing donation due to COVID-19 vaccine

Donate Life Missouri | Team Missouri (Mr. Lee)

- **Donate Life Missouri Facebook Page:** Mr. Lee asked the committee to discuss the Donate Life Missouri Facebook page at the May meeting and collectively determine what to do with the page
- **Donate Life America:** Engaging with Donate Life America as a whole is something for further exploration
 - What do we want to do with DLA?; What does it do for us?; How are we moving forward?
 - If the proposed Missouri legislation moves through, and can improve or expedite access to the funds, the need to explore opportunities to do more with the Donate Life logo is needed in addition to enhancing or increase public service announcements, etc.
- **State Fair:** Assuming the 2022 fair is in full swing, does the committee want to promote Donate Life Missouri at the event? MTN suggested conversations occur around these questions outside of GODAC quarterly meetings

Bylaw Review

- Bylaw review usually occurs annually and the last review was July 2020. Mr. Nicastro was asked to work on tightening up the language around elections. Mr. Nicastro accepted and indicated he is open to consulting with others, particularly around elections and vacancies. Discuss options at the May meeting

Donor Family Recognition Program (Mr. Collins)

- Event is April 12, 2022. Activities are throughout the day starting at 10:00 am and ending at 8:30 pm

Additional New Business Call

- DHSS Legislative Proposal (Mr. Nicastro) – Refer to Addendum 5 for discussion notes
 - The proposed language removes the obligation to check with the committee when it spends money in the fund; one of the three most important things the committee does. Current language provides a guarantee to Missourians that when giving a dollar, donating from their income tax refund, or donating more fund through the proposed bill there is a trustee of those funds. If the bill passes as currently written, it would not be the committee and allow the department to spend money from the fund indiscriminately and without consulting the committee. Mr. Nicastro asked the committee to oppose the bill, and direct the chair to send a letter to the general assembly with the committee's position
 - Mr. Nicastro moved that I draft a letter to the General Assembly on behalf of the Committee, for the Committee to review, opposing the passage of HB2680 and SB1146, specifically citing the amendment section 194.297 and the addition of the definition of potential donor in 194.210(2)(21)
 - Mr. Kovacs seconded the motion. It is moved and seconded that Mr. Nicastro draft a letter to the General Assembly on behalf of the Committee, for the committee to review, opposing the passage of HB2680 and SB1146, specifically citing the amendment section 194.297 and the addition of the definition of potential donor in 914.210(2)(2)
 - With no further discussion, the vice chairperson closed the discussion and a roll-call vote taken. The affirmative has it and the motion was adopted (6 Yeas, 1 Abstain, 1 Absent)

Conclusions: Informational & Actionable

GOOD OF THE ORDER

Closing Comments/Thoughts

- MAT was requested to provide a summary report and MAT indicated they will and also add a link to a digital PDF
- A standing invitation given for the May 12, 2022 dedication of the Family House and subsequent reception at the Missouri Botanical Gardens. The planetarium will be lit green in honor of Donate Life Month
- Send additional agenda items to Ms. Beatty

Conclusions: Informational and Actionable

NEXT MEETING

Agenda/Logistics (May 16, 2022 9 am – Noon; Runge Nature Center, Jefferson City, Mo., In-person Meeting)

- Agenda Items: Elections, Bylaws, Partner Updates, Hospital Representative Suggestion, Team Missouri, Missouri State Fair, Age and Donation Discussion, Education Efforts, Legislative Update (Presumed Consent)

Conclusions: Informational & Actionable

Adjourn

Meeting adjourned at 12:21 pm

Deb Simaitis, Vice Chairperson

Approved at 5.16.2022 Meeting except for Addendum 4. Addendum 4 approved via email vote in June 2022.

Committee/Partner Action Items

Action Items:	Person Responsible:	Deadline:
Introductions, agenda approval, and minute approval	Members and Partners	Ongoing
Dashboard & Financial Trends	Mr. Nicastro	Ongoing
Financial Report	Ms. Beatty	Ongoing
Box Instructions	Ms. Beatty or Mr. Collins	ASAP
Updates	Partners	Ongoing
Present Symbol vs. No Symbol on Authorization Data	Ms. Clark and Mr. Lee	May 2022 Meeting
Officer Election Nominees	Members	May 2022 Meeting
Committee Hospital Representative Suggestion	Ms. Clark, Mr. Lee, Mr. Kovacs	May 2022 Meeting
Government Relations Contacts to Mr. Bogle	Mr. Lee	ASAP
Government Relations Contacts to Department Liaison	Mr. Bogle	ASAP
Age and Donation Answer Questions (Refer to Minutes)	Member Discussion	May 2022 Meeting
Age Related Educational Information (Department web page)	Member Discussion	May 2022 Meeting
Donor Authorization for Transplant vs. Research	Ms. Clark, Mr. Kovacs, Mr. Lee	May 2022 Meeting
Donate Life Missouri Facebook Page Discussion	Members	May 2022 Meeting
Donate Life America Answer Questions (Refer to Minutes)	Members	May 2022 Meeting
Missouri State Fair 2022 Promote Donate Life Missouri?	Members	May 2022 Meeting
Bylaw Review-Vacancies and Elections	Mr. Nicastro and then Committee Review	ASAP
Draft opposition letter (HB 26890 SB 1146) for Review	Mr. Nicastro Draft & Committee Review	ASAP
MTN Summary	Mr. Lee	ASAP
Additional Agenda Items to Ms. Beatty	Members	April 22, 2022
Post Minutes to the Committee Box Account	Ms. Beatty	Prior to next meeting.

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Partner Reports/Updates

Department of Conservation (MDOC)

- Ms. Simaitis thanked MDOC for reserving a room for the May 2022 face-to-face meeting.

Missouri Department of Elementary and Secondary Education Report (Shelly Wehmeyer)

Learn Life Savers

- Promoting the Learn Life Savers program and making phone calls to school districts

Professional Development Day

- Will be held with health science instructors will focus on literacy

Missouri HOSA

- HOSA* 2022 state conference is scheduled in person for March 28-29. Nearly 1,300 students participated in the conference qualifier held earlier in the year. HOSA conference registration is between 700-750 students. If you have an interest in being a judge, contact Ms. Wehmeyer
- Missouri HOSA 2021-2022 State Officer Team will attend HOSA's Washington Leadership Academy in Washington DC on September 25-28, 2022
- Missouri HOSA's 2022 Fall Leadership Conference is scheduled for October 21-22, 2022 at Stephens College in Columbia, Missouri
- Missouri HOSA's 2022 Competitive Events Preparation Workshop is scheduled for December 3, 2022 at the Governor Office Building in Jefferson City, Missouri
- Find out more about Missouri HOSA and the full Calendar of Events at <https://missourihosa.org/>

Health Science Education Mentoring Meeting

- First in-person meeting is scheduled on September 24, 2022 at the Governor Office Building in Jefferson City, Missouri
- New Health Science educators are invited to take part in this program
- Each protégé is partnered with a seasoned Health Science educator/mentor

Annual Health Science Workshop

April 29, 2022

Addendum 1
GODAC Meeting 2.28.2022

LITERACY STRATEGIES THAT ROCK: NOT YOUR TYPICAL WORKSHOP

TOPICS INCLUDE:

- Vocabulary integration and activities for the Health Science classroom
- Working through text to find main ideas and summarize important content
- Tackling large amounts of technical language that can be overwhelming
- Project-based units to keep the classroom from becoming mundane
- Engaging Assessments: Presentations, Group Tests, and Summative and Formative Assessments


AGENDA:

9:00 AM: WELCOME

12:00 - 1:00 PM : LUNCH

3:00 PM: WRAP-UP

CLICK [HERE](#) TO REGISTER



MORGAN CONSTANT ELY, ED.S.

My name is Morgan Constant Ely. I graduated from University of Missouri- Columbia with an Undergraduate Degree in English Education and a master's degree in Curriculum and Instruction. I taught for 9 years in the Lee's Summit public school district as a 7th and 8th grade Language Arts teacher and a Reading Specialist. After leaving the school district in 2015, I became an adjunct instructor of literacy at the University of Central Missouri- Warrensburg. While teaching, I obtained my Education Specialist Degree in Human Services with an emphasis in Technology and Occupational Education. Currently, I teach all Content Area Literacy courses, Children's literature, and Response to Intervention for the Middle Level ELA students at UCM in Warrensburg, MO.

My passion is showing teachers how to incorporate literacy strategies into their classrooms, no matter the content area. Literacy is often thought of as a skill only to be taught in the Language Arts classroom. I want to change the way teachers view literacy and show them how using literacy strategies can enhance a student's learning in any classroom. I live in Lee's Summit, MO with my husband and 2 sons, ages 7 & 9. If I am not in the classroom, you can find me cheering them on from the sidelines or running carpool to practices.

- Two in-person meetings and virtual communication with assigned mentor, Content Expert, and DESE Health Science State Lead

Upcoming Virtual Healthcare Career Day

- First virtual Health Care Career Day held on February 25, 2022. Partners included the Chamber of Commerce and the Missouri Hospital Association. Over 6,100 students and advisors attended from Missouri and 11 other states. Currently in the planning phase. Date was chosen due to Career and Technical Education month in February
- DESE has partnered with the Missouri Hospital Association and the Chamber of Commerce to make this event possible

Saving Sight (Mr. Kovacs)

- Hospital development representatives are preparing for celebrations of life events held in April.
- Preparing for the Donor Family Recognition Program as part of the planning team. Donor family member, Theresa McClellan, will speak at the event
- Saw an increase of 109% in authorization this year compared to the same time last year
- Some of Saving Sight's surgeons are participating in a multi-year study thru the Eye Bank Association of America. This study is looking at how diabetes affects certain types of tissue grafts in corneal transplant procedures

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

Government Relations

- Senator Blunt visited MAT on January 14, 2022 to see the donor care unit first hand. He also had very directed questions regarding the 2019 liver allocation and 2021 kidney allocation changes
- MAT also shared the number of organs that remained at the St. Louis transplant centers vs. other transplant center outside of the St. Louis metropolitan area; in 2020, 48% of recovered kidneys were transplanted at one of the four St. Louis transplant centers. In 2021, this dropped to 36% of recovered kidneys. 2022 YTD – that number is 31%

Donor Care Unit

- MAT reached a new milestone over the weekend (January 26-27) with 2,500 eligible organ donors supported at one of their two donor care units. This milestone is a testament to donor families and to others around the country that indicated families would not authorize transfer to their facility. Today we are seeing our model replicated at ten organ procurement organizations across the country and an eleventh that will open later this year at MTN
- A second milestone reached over the same weekend was 30,000 tissue donors supported at one of their donor care units; a testament to donor families who say yes to donation throughout our service area

COVID Impact on Hospital Relations

- Staffing capacity has increased by 25% this year. Presence in the hospitals is increasing to ensure hospital service managers are available through the second shift (almost midnight) and rotating on the weekends. MAT continues to see a high prevalence of traveling nurses and therefore it is critical that a constant state of education occurs every time we enter a trauma center, as there are always new people. Some nurses are coming from other regions or areas with lower performing procurement organizations, and are not well versed in the appropriate procedures and protocols surrounding organ, eye and tissue donation. MAT is working to have a hospital service manager in the double a hospitals and level one trauma centers 18-20 hours a day

- Best practice change that started October 1, 2021, is when hospitals notify MAT prior to beginning brain death exams, goals of care conversation, or end of life conversations from 90 minutes to three hours. This change provides MAT ample time to get in front of the family prior to them making those decisions. This extra time allows for better conversations and education on their options
- A continued area of focus in 2022 is “pre-mentions.” This is when a physician or nurse pre-mentions donation. We find that this action has a negative impact of up to 20% on donor authorization. MAT staff is working with the hospitals to transition that conversation from the hospital staff to MAT or Saving Sight since Saving Sight does assist with cornea recoveries in specific parts of the MAT service area

Community Relationship

- Dedication of the new Family House is scheduled for May 12, 2022. All attending this meeting are invited. Originally, the dedication was planned for April, and due to supply chain issues delaying the build the dedication was moved to May. More information to follow through email
- Donate Life Day at Bush Stadium, previously called Transplant Awareness Day, is August 14, 2022; celebrating and honoring donor families across the region. MAT is the presenting sponsor and is the start of a three-year relationship with the St. Louis Cardinals
- MAT is partnering with 2006 World Series Most Valuable Player David Eckstein, whose family is impacted by kidney disease; several siblings have received a kidney transplant(s). The partnership includes radio spots played throughout the season (on KMOX) highlighting the need to join the registry

Midwest Transplant Network (MTN) (Ms. Clark)

Community/Stakeholder Engagement

- End-Stage Renal Disease Treatment Choices Learning Collaborative (Kidney Care Collaborative) – MO Hospitals participating: MU Health Care, Research Medical Center, Saint Luke’s Hospital, and Children’s Mercy
- True/False Festival Sponsor– March 3-6, Columbia, Missouri
- National Donate Life Month – April events and activities being planned
- MTN Hospital Awards Ceremony – May, Kansas City
- MTN Legacy Walk – Saturday June 4, WWI Museum and Memorial, Register for the walk through MTN’s website. This is a large event with thousands of participants
- Kansas City hosting North American Transplant Coordinator’s Organization (NATCO) Annual Meeting August 2-5. MTN is anticipating presenting at this meeting
- NKF Mid-Missouri Kidney Walk – Sunday September 25, Columbia
- MTN 50th Anniversary Celebration – October 2022 kickoff

Donor Activity and Updates

- COVID-19: Tissue processors did not accept the same volume of tissues due to the pandemic. This seems to be shifting again to more tissue recoveries. Seventy-two transplant from COVID Positive Donors
- Donor Care Unit: Projected completion date is late spring 2022. Anticipate first donor in early to mid-summer. The unit has seven beds and two operating rooms
- Data: Organ Donors – 373 (new record, prior record 341 in 2020); Organ Transplants – 981 (new record, prior record 929 in 2019), Tissue Donors – 1655 (record volume 1774 in 2020), January 2022 – 37 organ donors (new monthly record for January, previous 25 in 2018)
- Kidney donation is a priority and MTN operates under the premise every organ, every time
- Normally consent rates slip a little during the month of January. This did not occur in 2021

Missouri Kidney Program (MoKP) (Ms. Turner)

- MoKP is applying for a Delta Dental grant. If awarded, 1) it will provide financial assistance to pre-transplant kidney clients to receive needed dental work in order to get listed, and stay listed, on the kidney transplant waiting list, and 2) provide financial assistance to post-kidney transplant clients so they remain healthy. The goal is to lower a known barrier to kidney transplant
- MoKP has spent \$123,000 in private premium reimbursements to help transplant patients continue to have health care coverage. An additional \$6,000 was spent to assist transplant recipients and transplant donors defray living expenses associated with transplantation (recipient must be Missouri resident, not the donor)
- Transplant recipients also receive assistance with their co-pays for immunosuppressant and other medication not included in the aforementioned programs
- Kidney disease echo continues on the first and third Thursday of each month. It assists primary care providers with improving early detection of chronic kidney disease. An online program that physicians, nephrologists, primary care physicians, dietitians, pharmacist, nurse practitioners, and other health care workers attend. Format consists of a medical case presentation and discussion, a question and answer session, and the presentation of a health topic. This is especially helpful for rural health care providers
- Working with the National Kidney Foundation on the ShowMe CKD Intercept Project; educating physicians about testing and early diagnosis of chronic kidney disease in an effort to delay end-stage renal disease onset
- Valerie Hardesty is assisting with the Donor Family Recognition Program

Gift of Life (GOL)

- For new members, Life Savers and Transplant Mentors are flagship programs
- Retiree Andy Donnelly is currently experiencing stable health
- GOL will determine if mentoring improves transplant outcomes through a University of Kansas Medical Center research study
- The fundraiser, GoSeeDo, is May 7, 2022
- The long-term educational impact hope is that the programs contribute to more donor designations

Life Savers High School Outreach | Kansas City

- Completed 272 presentations first semester with a goal of 500 presentations for the 2021-2022 school year. As of February 1, we have 240 presentations scheduled for second semester
- Tammy Rock, Life Savers Educator, resigned in November. We wish Tammy best of luck in her new path. We have hired Kim Hamilton (kidney recipient) as a part time Life Savers educator and she will begin April 1

Transplant Mentors

Pattie Draper | New Transplant Mentors Program Manager | Began January 6.2022

- Pattie has been a social worker for the kidney transplant program at St. Luke's Health System for seven years. She brings a wealth of knowledge as we re-evaluate the program and make it stronger than ever. She originates from Kirkwood, MO and will also lend her knowledge regarding the St. Louis community

Learnlifesavers.com

School Board Presentations

- The online Learn Life Savers program continues to move forward and is close to 50% of this year's goal
- The eight Regional Captains set a goal of 50 total presentations for this school year
- Five volunteers recruited to assist with presentations within their assigned regions. Training was virtual on January 13 for the volunteers and included Life Savers educators Kelly Boeh and Suzy Ward as well as potential GODAC member Mary Ann Burns

- Missouri State Teachers Association Convention in Columbia was November 18-19. Thanks to DHSS, a free booth provided a means to distribute information about donation, as well as information about learnlifesavers.com. Booth workers were Kim Harbur, Suzy Ward, Virginia Beatty and Valerie Hardesty. Approximately 500 teachers attended
- Ballard School District declined because they believe it is a topic between the parent and the child
- Mexico School District declined. A member of the board was in favor of organ and not tissue donation. Concerns and myths addressed during the presentation.
- Stockton School District Board of Education member, a physician, indicated he had a 17 year old on a ventilator and that the teen's mother and grandmother could not decide what to do because they never had the conversation about organ donation. This is why the Learn Life Savers program is so important; the conversation matters! Stockton voted in favor last week
- The team is learning, growing, and evolving during the process

Life Savers High School Outreach | St. Louis

Cultivating Relationships

- Suzy Ward continues her efforts to build relationships with area St. Louis schools. Goal for the 2021-2022 school year is 50 presentations in 14 high schools. We thank Mid America Transplant for their continued patience as we develop this valuable program
- Ms. Suzy Ward will be presenting to the Washington University's Saturday Scholar Program on March 5, 2022. Attendees are primarily African American high school students interested in a medical career. After presenting the Life Saves program, she will ask students to be program ambassadors in their respective high schools; helping to open their school doors to receive the Life Savers program
- Suzy did 19 presentations representing 26 high schools first semester and second semester scheduled 33 presentations representing 38 high schools, with 20 presentations pending

Department of Revenue (DOR) (Gina Wisch)

- Responding to proposed legislation including the automatic registry enrollment (presumed consent)
- There are 607 passenger vehicles and 93 trucks with personalized organ donor license plates
- Data indicates an 11% increase in fund contributions between FY19 and 20, and a 27% increase between FY20 and 21

Digital Licensing (Mobile ID): The department is implementing a digital license or mobile ID. Legislation passed in 2020 authorized the department to pursue these options. More information available in Addendum 5.

- Individuals have the option to pursue a digital license available to all with a valid driver license. The digital license can be tied to renewal notifications on android or apple devices through the app store
- Individuals interested will receive a direct link
- The mobile system will match against DOR's system, uses some biometric identification (photo), and includes checkpoints throughout the process.
- User can limit information that is made available through the digital license
- The rendering of the mobile id will be nearly the same as the physical copy
- It will include the donor symbol
- Applicant has to choose what level of information for verification is used
- Issuance of physical copies will continue regardless if someone opts in for the mobile id
- Provides individuals the means to share information as a form of verification
- A free app to read digital license is available in respective app stores

- Mobile ID is available to individuals 21-47 years of age as regulated by statute. DOR is working to extend the eligibility for the mobile ID through age 69; the age group in the six-year renewal cycle. Once someone is 70 years of age or older, the renewal cycle is every three years
- Application process is the same as if at the license office, all of the same questions are asked
- Depending upon what the applicant chooses, they will receive a text or email (remote notification). This will be a simple text or email with a website link for detailed requirements and to initiate the renewal process
- The mobile ID is expected to be implemented late summer (July)
- More information about the mobile ID will be released later in the year
- DOR will update GODAC at the May 2022 meeting
- Four states have implemented and two or three others have initiated in addition to Missouri. Some states tie driver licenses to an electronic wallet system
- Mexico (the country) fully implemented a digital license and no longer issues physical copies
- Adoption of digital licensing will continue to grow in the United States

Electronic Notification: Late in 2021, DOR began implementing the electronic notification process by collecting data (text and email).

- Informs individuals how to access their renewal information
- Provides an website link to learn what documents are required
- Individuals choosing the electronic notification will no longer receive the renewal postcard
- The donor information will be on the website

Driver License and Heart Symbol vs. Registry Discussion Notes

- Ms. Beatty inquired on how many instances, over the last year, has MTN encountered this situation. Ms. Clark indicated she is not counting, as she is administrator only about 25% of the time. During the pandemic she felt it was more of an issue and happened a lot and perhaps angst was a compounding factor.
- Something good about the registry is that when people die they are removed. It is also the downfall. As an OPO I cannot go back and do QA, which is fine since the number representation in Missouri's registry is more accurate.
- Ms. Beatty indicated that it would be good to have some data as the public was saying no to the registry because they did not want a symbol on their driver license or id as they feared they would not receive the medical care they needed.
- Mr. Lee noted a January 2022 case in Springfield where the family pulled the driver license, showed there was no symbol, and did not move forward with donation.
- Mr Lee indicated that not having the symbol on the driver license might compound mistrust with the hospital and indicated he believes this to be true across all different ethnic groups.
- Donor families do not recognize, in their grief, that procurement organizations staff are not hospital employees; they see us as one in the same according to a recent survey of 300 donor families. When there is not a symbol, families see this as a trust issue; they feel lied to.
- Mr. Lee stated that donation affects people of all social, economic and educational backgrounds. Emotional status, education and that interaction with the medical field is a huge issue.
- Ms. Harbur inquired of Ms. Clark what questions she asks, exactly, in the state of Kansas. She also stated that sometimes less is more for the better good. Ms. Harbur indicated that she hears all the time in the classroom; if I have that symbol on my driver license what does that really mean. Clearing that up is very important. The question in Kansas is now; would you like to register as an organ, eye and tissue donor?
- Mr. Nicastro noted while removal of deceased individuals occurs in the database they are not deleted from the database. He inquired, would you (MTN and MAT) rather go in with a no or with a yes and no symbol and at least have a chance? He further The Department of Health and Senior Services lawyers as the time indicated that we would have to preview the fact there would be a symbol on the license if they said yes; resulting in the original really long question. Ms. Clark said that if they are not in the registry, they do not have a no, they just have someone that is not listed in the registry. Mr. Lee indicated they do not want to go in with an opt-out registry situation.
- Ms. Simaitis indicated that the one question was so long and confusing.
- Ms. Clark indicated she agrees with what everyone says and that this is a complex issue. And, to Mr. Lee's point, if they a family is saying the documents don't match, it is usually because they have had two or three other things that have not matched during the time their loved one was in the hospital. The registry record is only available to the OPO, and not all hospital staff, and the license is available to all hospital staff if on the person and to the family. While we all know here at this meeting that it is a myth if the symbol is on your license you will not receive medical care, some families do not believe that. And, they cling to the heart symbol as a sign of donation and coming to them with a registry printout is not as effective.
- Ms. Simaitis provided a person experience of a neighbor who wanted to be a donor and the spouse said absolutely not. So, she signed up through the license office and said no to the symbol so he would not know. She inquired of Ms. Clark if she could obtain data on, how many people in Kansas received their license and ask, what is this symbol?
- If you register online, you do not get a symbol unless you ask for one (through the online process).
- Before Kansas went to the one question, the two questions were: Would you like to be a donor? and, Would you like to be placed in our online registry? If they said yes to the first question, they got the symbol. If they said no to the

second question, MTN had to have their driver license to validate their decision. MTN was motivated for a different reason to get the questions changed in Kansas.

- Mr. Nicastro inquired of Ms. Clark if they have seen any difference in designation rate since moving to the single question in Kansas.
- The questions changed on January 20, so Ms. Clark does not have any data at this time. Ms. Clark will provide an update at the May meeting.
- Mr. Lee stated he appreciates the position of the state's lawyers to empower people with the second question. From MAT's perspective, it would be great if the symbol was automatic part of the licensing process. He further stated that it is interesting when people do not trust government at any level and do not trust healthcare, but when it comes down to what they do trust is their driver license to be the source of truth for them during these moments.
- Mr. Lee will work with their business intelligence office to see if they can capture any trend data over the past 36 months regarding families saying no because the symbol was not on the loved ones license and they were listed in the registry.
- Mr. Lee asked that at the May meeting to talk about the pros and cons off an opt-out registry. While there are a lot of differing opinions out there, MAT is not a supporter of an opt-out registry. They have not seen donation rates increase in Europe due to opt-out registries. There are transplant surgeons in the MAT service area that continue to be strong advocates for opt-out registries assuming this removes the family interaction and engagement because everyone is automatically a donor.
- Mr. Lee does not believe that Americans will ever relinquish their freedom of choice on whether or not they will be a donor.
- Mr. Lee stated it was great that Ms. Beatty, Mr. Bogle and the lawyers from MAT and MTN have ongoing conversations and it is great for relationship building between the Department and the organ procurement organizations as a whole.

GODAC Meeting 2.28.2022

Personal Experience with the Donation Process

- Upon her husband's death, Ms. Simaitis learned that age was a factor in donation. As a donor mom for over 20 years and a member of the committee for 11 years, she believed age was not a factor in donation. During this tenure, spoke to numerous groups of all ages and stressed age was not a factor.
- On the day of her husband's death, the nurse contacted the hospitals' designated tissue procurement organization and was told no because he is too old (77). The cut off is 75. Per the request of Ms. Simaitis, the nurse called a second time and reported that the tissue procurement organization said no he is too old. The following morning, Ms. Simaitis contacted the hospital's designated eye procurement organization on the advice of a friend and asked to speak to one of their leaders. The eye procurement organization took the information over the phone and, by that afternoon, a representative had recovered her husband's corneas.
- Ms. Simaitis mentioned the letters she received when her daughter became a donor and how many people she helped. She received a precious letter from the designated eye procurement organization about her husband's gift and that it will go with those letters and stay with her family. She feels there should have been more letters; thanks to him, someone walked again, a burn victim was helped, etc. We need to do a better job.
- Ms. Simaitis presented to the group the research she conducted for the meeting.
 - Donor Alliance in Denver, Colorado: "Even more remarkable, the oldest tissue donor in Colorado and Wyoming in 2019 was 103."
 - Donate Life America's questions and answers section: "Who can be a donor? People of all ages and medical history should consider themselves potential donors."
 - Donate Life Missouri website, she found the exact same answer.

MTN's Perspective

- MTN offered condolences to Ms. Simaitis for the loss of her husband. MTN explained tissue type criteria differ; the processor for each tissue type determines medically acceptable criteria. The time of the month, the tissue processors volume, and transplant center activity/needs all impact the process.
- Skin and bone tissue have different medical age criteria and can vary from day to day.
- MTN's educational platform does not want anyone thinking, "I'm 74 and I can't be a donor" when the next month the medical age criteria may change from 70 to 75. The tissue processors set the medical age criteria. Tissue processors slowed processing during the pandemic, and they might send out an email stating this month we are only accepting tissues from donors up to age 70 due to tissue transplant demand. MTN does not know on a particular day what the tissue processors will accept until after the medical history and age is determined and a call is made to the tissue processors.
- MTN's tissue donation authorization process is handled by telephone call and not face-to-face.

- Acknowledgement given to Ms. Simaitis who has trained call center staff and knows how MTN professionals should speak; MTN fell short and is will explore the situation. They acknowledged how difficult it was for Ms. Simaitis to think about and present the information shared.

MAT Perspective

- MAT recognized San Simaitis' steady presence at the committee meetings and as a huge supporter of the work. MAT is very cautious and intentional with language surrounding tissue donation and eligibility. They do not want to transport an individual to their facility and then not be able to steward the gift to a new home. COVID-19 has impacted elective surgeries, including orthopedic surgeries that benefit from donated tissue; causing weekly if not daily fluctuations in tissue needs. If a donor has a strong advocate for donation at the time of their passing, and MAT is unable to steward the gift(s) to a new home, MAT has to deliver a tough message. Families are rightfully upset. We need to talk with Ms. Simaitis and her family and learn from their experience.

Program Perspective

- Ms. Beatty expressed concerns from an educational perspective. We educate the public that age does not matter, and listening to the discussion, age indeed is a factor. Therefore, the program is considering removing the age information from the department's website. Mr. Lee asked the program to refrain from making changes at this time until after the May meeting.

GOL Perspective

- Ms. Simaitis nailed it; the piece, the gap, which was so difficult in a time that was already extraordinarily difficult; then, being an advocate, found out yes, he could donate something (research). This is where the issues lay. Taking time to reflect on the questions posed by Ms. Simaitis is essential. We serve in different roles in the organ, eye and tissue donation community and we need to discuss this in May. A shift, whatever that looks like, is important.
- Procurement and tissue organizations sit on the industry side which is very different than the donor family or transplant recipient side.

Saving Sight Perspective

- The organization has a lot of conversations about being good stewards of the gift(s). The criteria of donated tissue changes. At this time, Saving Sight is able to recover from individuals up to age 75 for transplantable corneas. A reason not to change the age language is because criteria changes over time. The doctors and surgeons that are transplanting the corneas set criteria; where the tissue processors set criteria for the tissues OPOs recover.
- Medical history is a factor. It is a difficult situation to balance. Any time a family is super passionate about donation; every effort to go above and beyond is made when communicated at the hospital level.

Transplant and Research

- The program noted if an organ, eye or tissue is not viable for transplant, the option exists for donation for research.
- Do OPOs and the eye bank pursue research opportunities after the age cut off for tissue donation?

- When calls are made, and the donor does not meet medical age criteria for organ and tissue donation, is consideration given to recovery for research?
- MTN does not pursue tissue recovery solely for research purposes and is unaware if there is a need for that volume of tissue exclusively for research. If pursuing recovery for transplant, then yes, MTN will seek authorization for research. If there is no eligibility for transplant, MTN does not pursue evaluation of the gift for research.
- When MAT seeks authorization for other components, they do include for research. This is a delicate issue for many families and Ms. Simaitis' family, in Mr. Lee's opinion, is a rare exception. Most research conducted right now is pancreatic which includes a lot of research intricacies. Mr. Lee indicated that he, Ms. Clark, and Mr. Kovacs would be happy to follow up at the May meeting.

Next Steps

- Mr. Lee asked for a deeper conversation and to consider how we can grow together to better understand the overall complexity of the issue. The committee is unique and this is a unique opportunity. How can we enhance the level of education for Missourians? The state program hopes, that collectively, a path to improve processes, from the call center to education, occurs and not just focus on one component.
- To OPOs and tissue banks, this may be an "industry" and this committee's structure helps bring balance to the discussion. It is also families, its people, its human beings, and its granting final wishes. We all need to make a difference. We need to start in Missouri," stated Ms. Simaitis.
- We are all positioned to help one another understand our unique perspectives and assess for improvement opportunities.
- The following questions need answers from the committee
 - When was age decided as a factor and who decided?
 - How long has age been a rule?

DHSS Legislative Proposal – Discussion Notes

- In November, the committee discussed changes and provided feedback. Mr. Bogle shared our feedback; specifically section 197.294.6 “consultation” changed to “may consult.” The proposed language removes from the Department the obligation to check with the committee when it spends money in the fund; one of the three most important things the committee does. Current language provides a guarantee to Missourians that when giving a dollar, donating from their income tax refund, or donating more fund through the proposed bill there is a trustee of those funds. If the bill passes as currently written, it would not be the committee and allow the department to spend money from the fund indiscriminately and without consulting the committee. Since the language has not changed since the committee recommendation, he opposes the bill and asks the committee to oppose the bill, and direct the chair to send a letter to the general assembly with the committee’s position.
 - Ms. Clark believes it is a threat. Mr. Kovacs shares the same concern.
 - Ms. Simaitis indicated she is unable to write a letter at this time.
 - Mr. Lee asked the following questions:
 1. What does the data show as the average annual expenditures over the past three-year period and trend lines for staff pay and actual programmatic expenditures against the fund balance?
 2. Has the committee expedited and facilitated the expenditures of funds to educate the citizens of Missouri on organ, eye and tissue donation, or has the committee stalled that process?
 3. Is the committee moving forward on the use of the funds for outreach, or should the department have greater latitude?
- Current language directs the department to contract with the organ procurement organizations and Mr. Nicastro stated “the department lawyers have done a very good job of standing in the way of the program spending the money for any other purpose.” The second purpose in this bill would expand the number of ways the program may spend the fund. The committee has never corporately said no, we do not want to do that, and Mr. Nicastro does not see the committee as an impediment.
 - Restrictions to exclusively use the OPOs have and are an impediment as is not leveraging the department’s outreach capacity. The committee should have the ability to review and decide how to increase outreach and education in the state. The committee needs to find a better way to streamline and consistently advise on the use of the funds.
 - The wording in section 197.294.6 was something Mr. Bogle had written because he thought it would be better wording. He acknowledged the language does change from a requirement to consult to an assumption to consult. The Governor’s office received the committee’s feedback. They felt the changed language is better from a legislative point of view. Mr. Bogle urged the committee to consider writing a letter stating that the committee wants this sub section left unchanged as to not impede the committee’s ability as fund stewards. He asked the committee to acknowledge support for removal of the word cadaver, fund options expansion, and not in support of changing language related to the committee.
 - In the House the sponsor has to request the bill move to committee, in the Senate it is automatic. The sponsor has until the end of session to try and get the bill passed. Bills may or may not pass when filed in late February. There is time to amend the bill if this is truly a stumbling block, and the committee believes this should not pass with this language in it; seek to amend.

- A Governor supported bill being opposed by one of the Governor's committees may have unexpected outcome(s). The committee's voice is important and there is time to express the committee's perspective; to make changes during the legislative process; outcomes are not predetermined. The Governor is behind this specific language right now, and the department can accept and forward feedback. If the committee does release a letter, the department can refer back to previous feedback provided.
- Missouri statute indicates that the committee is an advisory group to the department, so the letter needs to go to the department director or to the legislative liaison and ask that they take the information forward. Private citizens can contact their legislator and advocate.
- Mr. Lee indicated the OPOs are strong supporters of removing the word "cadaver." The OPOs have concerns about some of the language regarding organizations that can handle deceased bodies. There is also a concern about recovery of organs from aborted fetuses. The latter is very negative and not medically possible and implicates, by including the language, that it is plausible. The abortion piece is equally as concerning as past bills about recovering organs from executed prisoners. Again, not medically plausible. If possible, in this latter circumstance (executed prisoners), the recipient would have to authorize acceptance of this high-risk organ. The abortion language casts a shadow on the overall process of organ donation.
 - Language about abortion is an addition to the bill after its introduction. Sharing of OPO concerns occurred earlier in the year. Perhaps remove the entire definition of potential donor since prospective donor is an existing definition. This is the first year for filing this proposal and it is typical to see amendments as reviews are made and concerns raised. Consider using the legislative process and ask for amendments rather than destroy a bill and call it inferior.
- Ms. Simaitis suggested adding this to the May agenda to discuss suggested language. This is a problem because either the General Assembly will have ended its session or there will only be a few days left.
- Ms. Beatty suggested a compromise of submitting a letter to the department's legislative liaison about the sections that are unsatisfactory and providing suggested wording.
- Ms. Simaitis stated the word "may" does not bother her, as the group is an advisory committee. We asked that the committee be included and we have been.
- Mr. Nicastro disagrees that our only responsibility is to advise the department. Our ability to advise the General Assembly can only happen annually through the report. He opposes the bills present language. He asked for an amendment to the motion to direct the letter elsewhere and requested the letter be public record. An important committee function is to advising the department and consult on the fund spending. Mr. Nicastro's opinion is that the department will spend money and cast the committee aside one day and therefore requests the committee write the letter.
- Ms. Burns asked for further discussion as she is uncertain if she has enough information to vote. She read information about committee responsibility; one of which is to recommend priorities of expenditures. She asked what kind of responsibility from the genesis of this organization, for this committee, are the expectations.
 - The section under discussion is the actual spending from the fund, not recommending expenditures. Under the proposed bill, the department is not required to ask the committee about proposed expenditures.
 - Mr. Lee asked for clarification on what the letter will address. The letter will address multiple issues that cause the committee to oppose the bill; including fetal tissue and committee language. Mr. Lee supports the committee writing a letter as long as the committee looks at a much broader definition of who can be the funded agencies. Mr. Nicastro offered to write the letter after Ms. Simaitis declined as long as someone double-checks it. Mr. Lee offered to help assist in drafting the letter and include things that the committee believes is great about this bill. Ms. Simaitis suggested an emergency meeting in one to two weeks to give Mr. Nicastro adequate time to word his motion. Mr. Nicastro declined.