



# Governor’s Organ Donation Advisory Committee Minutes

12.8.2022 | Mo. Kidney Program, Columbia, Mo. | WebEx Meeting ID: 2458 421 1475



**Note Taker(s):** Virginia Beatty  
**Attending Members:** Deb Simaitis, Peter Nicastro, Mary Ann Burns, Kevin Lee, Lori Clark, and Virginia Beatty  
**Absentee Members:** Jan Finn  
**Partners/Guests:** Annie Kuhl, Tara Whittington, Kim Harbur, Laurie Hines, Joshua Allee, Gina Wisch  
**DHSS Staff:** Ian Collins and Sandra Hentges  
**Called to order:** 12:36 pm by Chairperson Kevin Lee. Quorum present.

## WELCOME/APPROVALS (Introductions; Approval of Agenda and Minutes | Informational & Actionable)

- Missouri Kidney Program staff introduced and thanked for hosting the meeting. Tara Whittington, RN is a member of Midwest Transplant Team and a recipient family member
- Legislative session added to the Agenda and approved as amended
- Change the Real ID deadline from March 2023 to May 2023. September 2022 minutes approved as amended

Action Items	Person(s) Responsible	Deadline
Draft December meeting minutes	Virginia Beatty	ASAP

## Mission Moment (Informational)

- Guest speaker, Ms. Tara Whittington., helped ground the committee through the Mission Moment. She shared her personal experience with organ donation and her role with Midwest Transplant Network
- Ms. Whittington is a Family Services Coordinator and Hospital Services Coordinator and a nurse for nearly 20 years. She supports the families that are transitioning from the hospital through the donation journey. Her responsibilities also include mortality reports and chart reviews for several hospitals
- Organ and tissue donation impacts her personally. Her father-in-law was a cornea donor in 2010. Her father received the gift of life through a kidney transplant in 2017, and her mother became a cornea donor when she passed in May 2022. Through the transitioning of, Ms. Whittington was able to assist her father’s through the transplant journey and from it came a renewed relationship with her father. She was able to guide him through the process, be with him at the hospital and at medical appoints. Her father is doing well. She recognizes how blessed her family was and is because someone was willing to give the gift of life to her father
- Her father enjoys public speaking, and was the keynote speaker at the kidney walk in 2018 held in Columbia, Mo.

Action Items	Person(s) Responsible	Deadline
Recruit Mission Moment Guest	Kim Harbur	Next Meeting

## Reporting (Informational & Actionable)

### Appointment Status

- Mr. Joshua Allee submitted his application. Ms. Beatty has reached out to the Boards and Commission Office and awaiting a response. Other individuals have submitted their application for the donor/recipient family position. One is a doctor from Washington University who is a kidney recipient. Committee needs to be sensitive to and work toward geographic and demographic diversity. We currently have members from Kansas City, St. Louis, Columbia/Jefferson City, and the Lake of the Ozarks areas.

**Revenues & Trends** Tabled

**Dashboard** Tabled

**FY23 Budget Report** No questions

### High School Education Project

- Mary Ann Burns and Kim Harbur presented at three regional superintendent meetings (Macon, Rolla and St. Joseph). Meetings are held monthly and there are eight regions total
- After the ten-minute presentation, superintendents were given the options of saying: 1) yes, we will do this, 2) provide a teacher’s name and contact information, or 3) present to the district school board of education
- To date, 51 school districts have said yes, 13 have requested a presentation, 2 are sharing the information with their teachers, 1 districted chose not to vote, 1 district provided the information to their curriculum director, and

5 districts said no. Of those that said no, 2 districts said the topic should be discussed between the parent and the student

- Team captains will meet in Columbia, Mo. in January and develop a three-year plan with the goal of completing the project by 2025
- Ms. Harbur noted that Mr. Ian Collins and the volunteers in region six are doing an amazing job. She also noted that her team will complete all of her regions by the end of 2023
- Ms. Suzy Ward presented to the HOSA leadership Team in Columbia Mo., on November 4, 2022
- At the March HOSA conference, looking to host a breakout session about presenting to school boards at specific geographic locations. Send HOSA sponsorship request to Mid-America Transplant
- Gift of Life will be fully staffed as of January 2023.
- The teacher recently shot and killed in the St. Louis area was one of the teachers working with the Life Savers program. On a personal level, Ms. Harbur expressed how difficult that has been
- Ms. Clark suggested recruiting her son to help. Mr. Collins will contact him as perhaps he can assist with the Columbia School District

#### **Partner Q & A**

- Reports were uploaded and available for reading prior to the meeting
- Midwest Transplant Network expects fewer tissue donors as tissue demand is down; eligibility is down a bit too as the previous numbers were high due to COVID deaths. Mid America Transplant is experiencing the same. There is still a strong demand for skin donations for burn victims. There is soft demand/interest in organs from extended criteria donor (usually over the age of 60)
- The primary objective of the group “Organize” appears to be assuring that the United Network of Organ Sharing and the Organ Procurement and Transplantation Network board are different so that there is a separation between policy development and implementation and technology
- To tour Midwest Transplant Networks’ Donor Care Unit, scan the QR code in the report
- Missouri Kidney Program received the Delta Dental Grant award and announced funding availability this week. The program is waiting for applications from specific renal social workers. More information will be available at the February meeting
- Mid-America Transplant is in a Chief Executive Officer (CEO) transition. Ms. Susan Diane Brockmeier began her career as the fourth employee of Mid-America Transplant in 1986 as a coordinator in Cape Girardeau. She was primarily responsible for the design and implementation of both donor care units, led the organization to receive the Malcolm Baldrige Award in 2015 and in 2021. After 36 years of service she is retiring

#### **SRTR & Transplant Center Performance Website Tool**

- No update on the web-based performance tool at this time. Dr. Krista L. Lentine is working on the public interface project, and Mr. Lee hopes to have an update at the February meeting

#### **2023 Legislative Update**

- Over 80 prefiled received. Of interest to the committee is HB 289 which repeals the COVID-19 language that passed during the regular 2022 legislative session
- Legislative updates will be emailed to the committee after the first of the year
- There are rumors that Representative Joe Dahl is trying to move forward with opt-out registry legislation again in 2023 (presumed consent). Mid-America Transplant has reached out to her office and expressed their concerns. Opt-out registry means everyone is registered and if you do not want to be registered, you must opt out. Mid-America Transplant will continue to discourage an opt-out registry in addition to discouraging Dr. Chapman from Barnes Hospital, a proponent of an opt-out registry.

#### **Action Items**

	<b>Person(s) Responsible</b>	<b>Deadline</b>
HOSA sponsorship information to Mid-America Transplant	Kim Harbur or Virginia Beatty	ASAP
Contact Ms. Clark for Learn Life Savers volunteer	Ian Collins	ASAP

#### **UNFINISHED BUSINESS** Informational & Actionable

**Bylaws** Tabled

**SWOT/SSC\*** (Kevin Lee)

- A threat and opportunity is the access and distribution of funds

- Prior to passage of 2022 legislation (SB 710 and HB 2333), only the two certified organ procurement organizations (OPOs) serving Missouri could apply for the funds through the Department
- Program can now contract with OPOs and with other entities. For example, the program could contract with Gift of Life to provide education or with a marketing group for social media messaging development
- The Governor signed the legislation that became effective August 28, 2022. The program is working on a letter of agreement with Health Literacy Missouri to review materials
- Fiscal year expenditure is limited by spending allocation/authority given by the General Assembly. The maximum amount for a letter of agreement is \$10,000 for the fiscal year per entity per activity. The Department can send out bids if under \$50,000. Each contract level has its processes and complexities
- The program cannot ask for more spending authority until the current allocation is spent consistently
- Missouri statute protects the fund from being swept

#### **Donate Life Missouri Facebook Page**

- The Facebook page has been dormant for nearly three years
- This is an opportunity for the Department to potentially contract for a third party administration of the page

#### **Donate Life America Team Missouri**

- Mr. Lee requested discussion be held as a subcommittee and asked to include LaKeisha Coleman from Mid-America Transplant and Nicole Asquith from Midwest Transplant Network as part of that subcommittee

#### **CMS Metrics**

- OPOs are evaluated on two metrics
  - Donation rate (number of donors)
  - Transplantation rate ( number of organs transplanted)
  - Numerator: number of donors with at least one organ transplanted
  - Denominator (determined by the Centers for Disease Control and Prevention; CDC): eligible deaths under the age of 75 with a cause determined to be consistent with medical eligibility for organ donation. CDC bases the denominator on county-by-county death record review. There is an 18-month lag in data. For quarter one of 2023, Mid-America Transplant and Midwest Transplant Network will receive their performance evaluation from Centers for Medicaid and Medicare (CMS) based on data from 2021
    - Current contract cycle is August 2022-August 2026. At the end of that cycle, the top 25% (+/- 5% confidence interval) will receive Tier 1 status and an automatic four-year contract renewal
    - OPOs with performance scores less than Tier 1 but above the median are classified as Tier 2 and able to reapply for a four-year contract. Tier 1 OPOs will be able to apply for Tier 2 territories too. OPOs that fall below the median, Tier 3, will be decertified and ineligible to contract with CMS to operate as an OPO in the U.S. Tier 3 territories may go out for bid or delegated to another OPO. Interpretive guidelines is pending from the national Department of Health and Human Services and CMS
    - Mid-America's business intelligence and business analytics department applied for and received access to the county-by-county death record review. With this data, they are confident they can project the donation rate. Stratification of the transplantation rate is difficult and based on donor age and other factors set by CMS. Mid-America Transplant is not comfortable making projections on transplantation rate
    - It is unclear how many OPOs will be in Tier 3. Many OPOs have made improvements and others are merging with one another. As of January 1, 2023, there will be 56 OPOs. Mr. Lee agrees with Ms. Clark that there will be more friendly mergers and consolidation. It is unclear how CMS will evaluate mergers at the end of the current contract period

#### **Missouri State Fair**

- State fair planning begins the end of January first of February 2023
- Volunteers needed every day to man booth; ideally two individuals per shift
- Mr. Collins will provide dates, time parameters, possible building location, and sponsorship level at the next meeting
- Gift of Life may have volunteers willing to assist. Other partners said the same

#### **Donor Family Recognition April 11, 2023**

- Estimated catering budget is \$800-\$1,000 for dessert items and beverages
- Working with local downtown businesses (restaurants) and not major chains to secure discounts for families

- Wufoo registration form completed and approved. Link included in the donor family letter as a QR code. Registrations will come directly to the Organ and Tissue Donor Program. The option to register by calling the toll-free number is also included
- Capitol day is not a part of the official Donor Family Recognition program. Yet, families can choose to attend. Any person visiting the state capitol on April 11 will be able to visit and learn from partners. Tables and chairs are reserved for 9:00 am to noon.
- Truman building conference rooms will open at 2:30 pm for families to check in, work on crafts, and program
- Governor’s garden will be earlier than last year with speakers and time for donor families to visit
- Bakers Creek Heirloom Seed Company is a sponsor and providing seed packets. Staff have reached out to the Department of Conservation and awaiting a response
- Ms. Harbur complimented Mr. Collins on a job well done

**Recommended Language (Brain Death)**

- When working with nurses and other clinical positions the current language is appropriate
- When working with public and other non-clinical positions, it is appropriate to say deceased organ donor patients eligible for transfer
- Ms. Simaitis is comfortable with the language recommended by Ms. Clark as it is respectful to both donors and donor families
- Use the non-clinical language for education purposes
- Language still needs to be reviewed by Midwest Transplant Network management

**Action Items**

Action Items	Person(s) Responsible	Deadline
Establish a Donate Life Team Missouri Subcommittee	Virginia Beatty	ASAP
Provide State Fair dates, times, building location, and sponsorship level	Ian Collins	February Meeting
Confirm recommended brain death language approved by Midwest Transplant Network	Lori Clark	February Meeting

**NEW BUSINESS (Informational & Actionable)**

**Delta Dental Grant (Missouri Kidney Program-MoKP)**

- Award received. Applications requested from renal social workers
- More information available at the February 2023 meeting

**My Transplant Ready Workbook Update (MoKP)**

- Ms. Beatty and Ms. Hines met with Health Literacy Media (HLM) about the workbook rewrite. MoKP will establish a contract
- Revisions include enhancing the section on multi-listing, living donation, overall readability, and making sure the revised version addresses health literacy
- Contract process is waiting for a proposal from HLM. After the contract is awarded, Ms. Hines and Ms. Beatty will pull together a workgroup to begin workbook edits
- Ms. Harbur inquired if there are Medicaid or Medicare barriers to multi-listing. Ms. Clark stated a person can only list with one transplant center within an OPO service area. Therefore, someone cannot list at Barnes and St. Louis University because they are both within Mid-America Transplant’s service area. As OPO contracts and service areas continue to evolve, including friendly mergers, this needs consideration when revising the workbook. If listed at multiple transplant centers in one service area, you remain at the same spot on the waiting list for that area. Moreover, consider the new 250 nautical mile radius. It appears the listing policy has not caught up with the new allocation policies
- Ms. Hines indicated that if a person does not qualify for Medicare and only have Medicaid, there are transplant centers that will not transplant a person because they do not have both.

**Action Items**

Action Items	Person(s) Responsible	Deadline
Delta Dental Grant Update	Laurie Hines	February Meeting

Establish My Transplant Ready Workgroup

Laurie Hines and Virginia Beatty

After contract established.

**GOOD OF THE ORDER** (Informational & Actionable)

**Closing Comments/Thoughts/Suggestions**

- Michala Stoker is no longer with Midwest Transplant Network because the organization outgrew her skill set. Based on news reports, changes to criteria, etc., Midwest Transplant Network wants the public affairs department lead by a director with formal training in marketing, public affairs, etc.
- Ms. Hines thanked Ms. Clark for inviting her to be part of the kidney collaborative. There are multiple learning opportunities every week
- Primary meeting dates and alternate dates are on today’s agenda. Mark your calendar. The June meeting is in-person on June 8 as there were too many conflicts on June 1. No alternate meeting date for June
- Annual Missouri Kidney Walk in September and Ms. Clark will include the Organ and Tissue Donor Program for the September 2023 event
- The Wood Houston Bank in Marshall and Cape Girardeau has an annual project with employees. In 2022, it was a donor registry drive. They are going to make it an annual project every April and invite their patrons to participate
- Ms. Kuhl noted that the Walgreens project consisted of talking to a lot of people. People were proud to show they had the donor symbol on their license. Ms. Kuhl’s team reminded them to have the conversation with their family
- Ms. Clark will contact Mr. Collins about additional call center training (dynamic searching nuances)
- Mr. Allee reported that they are seeing record numbers of RSV and Influenza at rates normally seen in February. Several hospitals are out of staffed beds. Ms. Clark indicated the University hospital has record volume of adult patients with RSV and some are testing positive for COVID too
- The Family House is almost full and to date able to accommodate all requests. The Family House staff felt the loss of a liver transplant patient whom never fully recovered after surgery
- Mr. Peter Nicastro is dealing with some health issues and all are asked to keep him in their thoughts
- Safe travels and happy holidays

**Action Items**

Action Items	Person(s) Responsible	Deadline
Add 2023 meeting dates to calendar	Members and Partners	ASAP
Annual Missouri Kidney Walk Invite	Lori Clark	Summer 2023
Contact Mr. Collins about Call Center Training	Lori Clark	ASAP

**NEXT MEETING** (Informational & Actionable)

**Agenda/Logistics**

- Agenda Items:
  - Standing Reports and Project Updates
- February meeting will be virtual

**Action Items**

Action Items	Person(s) Responsible	Deadline
Develop Agenda	Kevin Lee and Virginia Beatty	January 2023

**Adjourn (Informational)**

Meeting adjourned at 3:02 pm	Kevin Lee
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