



Governor’s Organ Donation Advisory Committee Minutes

9.9.2022 | 920 Wildwood Dr., Jefferson City, Mo. | WebEx Meeting ID: 2451 801 9605



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: Kim Harbur, Laurie Hines, and Shelly Wehmeyer
DHSS Staff: Ian Collins
Called to order: 9:31 am by Chairperson Kevin Lee. Quorum present.

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

- Agenda approved as presented
- February 2022 minutes Addendum 4 approved via email vote. May 16, 2022 meeting minutes approved as presented

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

Mission Moment (Informational)

- Implemented by the Chairperson to help ground the committee each time they are together
- Mr. Kevin Lee shared stories of two children who need a tissue transplant to repair an open space on the spine. One child received a skin graft in utero and the other did not. One family remains hopeful their child will receive a transplant and the other child is doing well. The Family House has seen an increase in kidney recipients of color, from 12% to 26%. When units are available, pediatric bone marrow transplant families also stay
- Ms. Mary Ann Burns shared her great niece’s story, a three-time kidney recipient celebrating her birthday today
- Ms. Lori Kramer highlighted Ms. Camryn Crist, advocate, whose grandfather was a cornea recipient
- Ms. Kim Harbur shared her son’s story and his liver transplant 26 years ago when only eleven months old
- Mr. Ian Collins shared his experience at a recent Missouri State Charitable Campaign event where a number of state employees knew someone in need of a kidney or who donated a kidney

Action Items	Person(s) Responsible	Deadline
Recruit Mission Moment Guest	Lori Kramer	Next Meeting

Standing Reports Q & A (Informational & Actionable)

- Mr. Joshua Allee’s application as the hospital representative is still pending. Ms. Jan Finn plans to resign and needs to submit a formal resignation letter. To avoid an institutional knowledge gap, the committee needs to begin thinking about succession planning
- Dashboard
 - Enrollment is dependent upon the individual’s birthday. When an un-emancipated minor turns 18, their recorded as an adult. The denominator is 16 and 17 year old population estimate from the 2020 Census. Note raw numbers and scale. Enrollment in higher education institutions is dropping and birth rates are also lower
 - Several drivers testing locations have closed in the St. Louis area, driving enrollments to fewer license offices
- Organ Donor Program Fund Financial Trend
 - The fund is protected by an existing statute and cannot be swept
 - The new legislation, effective August 28, 2022, allows for \$1 or more contribution at the license office
 - As of August 31, there was a balance of 2.98 times the annual expenses
 - State legislature determines spending authority. The program needs to spend the full amount consistently before requesting an increase in authority
 - Mid-America Transplant (MAT), as an employee benefit, offers to reimburse employees the specialty plate fee if they want to obtain a “Be An Organ Donor” plate; 14 employees have opted for this benefit
 - Perception is that providing donor families a license plate is an incentive to donate which is illegal
 - Collectively we want to avoid any perception that donor families are receiving incentives
 - Mr. Nicastro mentioned the thank you card his family receives from the Children’s Trust Fund specialty plate and suggests the Organ Donor Program do the same. Mr. Nicastro is going to save the card for future

reference. Ms. Beatty and Mr. Collins will contact the Children’s Trust Fund and discuss the agreements they have in place that allow for the necessary data sharing. If the program can make the arrangements, Mr. Lee offered their agency volunteers to help write and mail out thank you cards

- As the Real ID deadline approaches, May 2023, it is an opportunity to engage with people. The Department of Revenue’s materials about the Real ID all discreetly contain information about the symbol and registering
- Organ Donor Program Fund Expenditure Reports for FY22 and FY23
 - Reviewed by committee; no question about the FY22 budget report
 - Details of expenditures and comments included in handouts
- High School Education Project: Presentations at superintendent regional meetings will begin this fall. Hopefully some superintendents will say yes to implementing the program eliminating the need to present to their school board; reducing the number of presentations for team leaders. Currently Ms. Burns and Ms. Harbur are refining materials
 - Approximately 30 school boards have returned the participation letter; three voted no, one is in the hands of a curriculum director because the board does not vote on curriculum; and the rest are a yes
 - Ms. Mary Ann Burns, Ms. Wehmeyer, and Ms. Harbor will present at superintendent regional meetings. The goal is to complete three presentations this fall with the superintendents having the option to say: 1) yes, we are going to implement, 2) provide teacher contact information, or 3) request school board presentation. This will hopefully reduce the number of school board presentations and increase the number of schools presenting the information to their students
 - Ms. Harbur, Ms. Ward, and Ms. Wehmeyer will present at the November HOSA leadership conference, giving the students an opportunity to become advocates and present to school boards; the lead advisor for Collegiate School of Medicine & Bioscience is Ms. Ninfa Matiase (Nin-fa Mat-e-as-a). Ms. Harbur noted there is a lot of power in a star student(s) standing addressing the school board
 - A St. Louis School District Board presentation will be September 27; Ms. Ward and Ms. Kim Hamilton will present and pitch Learn Life Savers, Life Savers in-classroom, and Life Savers-virtual options. The district has approximately 26,000 students. Ms. Hamilton is an African-American kidney recipient and she has one son who plays for the Kansas City Chiefs and another who is a professional dancer who opened the BT awards this year. She is a great speaker and organ donation advocate
 - Feedback from teachers that have used the Learn Life Savers program have liked it as did the students
 - Receiving interest from other schools across the country
 - Ms. Camryn Crist is a volunteer presenter for Region 6.

Action Items	Person(s) Responsible	Deadline
Post standing reports to GODAC Box Site	Partners & Members	Before Next Meeting
Contact Children’s Trust Fund	Ian Collins & Virginia Betty	

PARTNER UPDATES (Informational & Actionable)

- Reports reviewed prior to the meetings and the discussion summary is in Addendum 1

Action Items	Person(s) Responsible	Deadline
Share oral health data and costs from past 10 years	Kevin Lee	Submit to Ms. Hines ASAP
Draft data report and place on Box site for quarterly updates	Virginia Beatty & Ian Collins	Before Next Meeting
Determine which OPO staff should have access to Box Site	Kevin Lee & Lori Clark	ASAP
Material with QR Code to Ms. Clark	Ian Collins	Prior to the walk
Recommended language: death donors and DCD donors	Lori Clark	Next Meeting
Partner Reports uploaded to Box site	Partner Representatives	November 21, 2022
Kansas University Mentor Study Results	Kim Harbur	September 2023
Referral data by race (every level of recovery/transplant)	Laurie Hines & Virginia Beatty	Undetermined

UNFINISHED BUSINESS Informational & Actionable

Bylaws

- Tabled

SWOT/SSC* (Kevin Lee)

- Opportunities:

- Instead of white washing an identified issue or issues that may be controversial, expose the problem(s), accurately describe the problem(s) in minutes, and work together to solve issue(s)
- Discussing the Donate Life Missouri Team, Facebook page, public service announcements, and social media needs to occur and a plan developed. How do we broadly reach the public? What can the committee and department control?
 - The committee myopically focused on the number of registrants in the past. Focus needs to be on the eight steps to convert individuals to action. One measure would be number of impressions
 - The committee needs to ensure that education and outreach occurs in all Missouri counties
 - What are other impressions? How are we impacting the population?
 - While AI may indicate the need for more social media, what does that actually mean? Does it mean TikTok, Instagram, Facebook, or some other key component? What is the message? What is reasonable?
 - A recommendation is to share a story a month or quarter; OPOs could feed stories to the program, the program's website has the capacity for individuals to share their stories, and the program is working to improve story-sharing functionality.
 - A 15-20 minute video focused on the African-America community is available and the link shared
 - The program plans to develop one-to-two minute videos and podcast; including stories of families that lost their loved one while waiting
- Inform the public about Missouri's two outstanding OPOs; not differentiate between the OPO and hospital staff, just that Missouri does a good job and is a benefit to the public in the region
- Potential threats
 - Fatty liver disease in the United States and the need for liver transplants increasing
 - National attention. Effect of the negative national attention on organ procurement organizations is unknown
 - OPO vs. Hospital Staff. Unless families have had some previous exposure, a medical background, or physically see a medical team fly in to transport their loved one, they believe the OPO staff and hospital staff are one in the same. The public is unaware of the difference between OPOs and hospital staff, that each OPO functions differently, or that the medical teams are different between treatment and then organ recovery
 - Centers for Medicare and Medicaid Services (CMS) released new metrics. MAT is seventh in both donation and transplantation categories and MTN is in the top three. Discuss at the next committee meeting
 - Transplant Wait Time at Missouri Transplant Centers. Speculation is that Missouri transplant center wait times are long in addition to a health access and equity issues. Additional speculation is that poor white and black families are adversely affected. Committee needs racial and economic breakdown of wait times
 - Single Listing vs. Multi Listing. Being financially poor and not understanding how to get listed at one or multiple centers or how to compare centers is also a potential threat

2023 Donor Family Recognition Program (Ian Collins)

- All locations secured
- WuFoo form under development for RSVPs
- The Capitol event will be in the morning and an unofficial part of the day's activities. Partners can interact with Capitol visitors, staff, and legislators. Reservations confirmed.
- Picture wall and ceremony will be at the Truman building (same location as 2022 event)
- Mr. Collins will share estimated catering cost at the December meeting, and handle ordering and delivery
- Capitol Dome lighting request submission is scheduled for January
- Governor's Manson lighting request submission is scheduled for March
- The program is discussing expansion and including a state Living donor recognition program
- The Association for the Society of Transplantation has a new certification for employers supporting living donation and recommends the program check into this opportunity
- Ms. Harbur complimented Mr. Collins for doing an excellent job with the event planning

SRTR & Transplant Center Performance Website (Kevin Lee)

- Scientific Registry of Transplant Recipients (SRTR.org) is a U.S. Department of Health and Human Services subcontractor
- The organization gathers transplant hospital performance data into a central repository

- Feedback from recipients and donor families solicited for the first time by SRTR. Citizens do not know how to compare transplant centers in order to choose the best option for them. Therefore, they are relying on their primary care physician to make a recommendation. They do not know how many times or why their transplant surgeon turned down a kidney for them. SRTR is working to build more transparency and be more patient focused
- How can we inform Missourians so they can make the best decision? How can we use the SRTR tool? How do we present information on how to compare the data and get multi-listed, thus improving equity and access?
Schedule continued discussion and SRTR data demonstration for the next meeting

Donate Life Missouri Facebook Page

- Tabled

Donate Life America State Team

- Tabled

Action Items	Person(s) Responsible	Deadline
Obtain videos shared on Facebook during Donor Family Recognition Program for website	Ian Collins	Undetermined
Catering costs to OPOs	Ian Collins	Next Meeting
Diane Brockmeier’s Senate Testimony Link to Committee	Kevin Lee	Undetermined
Donation and the African-American Community Video link	Ian Collins	Undetermined
Wait time data by race	Virginia Betty & Laurie Hines	Undetermined

NEW BUSINESS (Informational & Actionable)

New Threat – Fatty Liver Disease

- Refer to SWOT section

Capitol Visit

- Ms. Burns recently visited the state capitol building with her grandchildren and met Governor Parson; he is receptive to organ donation, happy she serves on the advisory committee, and mentioned how moved he was when he visited donor families and heard their stories at a state event (Donor Family Recognition Program). When there is opportunity to invite the Governor, we should. We also need to capture donor family stories

Programmatic Recommendations

- Ms. Beatty reminded members that part of the committee’s responsibility is to make formal recommendation to the Department related to organ, eye and tissue donation; what to continue, stop, or start. Clear recommendations the Department can assist the program to focus with limited resources
- SWOT will remain an ongoing program recommendations and guidance process with programmatic action items

Symbol vs. No Symbol

- Kansas started with two questions and changed to one question at the license offices in September 2021. Kansas online questions did not change until January 2022; meaning no consistency in questions until January 2022. Kansas is experiencing a delay in evaluating the change impact. It is also unclear if Kansas is diligent about removing individuals who have passed or if the Kansas registry numbers are accurate. MTN operates the Kansas registry and Ms. Clark continues to learn about the process. A legislative change may be required so that the vital records data for deceased individuals can help clean the Kansas Registry dataset
- Ms. Gina Wisch provided the symbol vs. no symbol data for state fiscal years 2017-2022 and includes the possible responses by fiscal year by county. The trend in all categories is slowly rising. The data is a potential indicator that collaborative efforts are having a positive impact with overall public acceptance of donation. For FY2022, 7,784 people said no to the symbol; if the symbol was not an option, would their decision been different?

Registry

- Ms. Clark noted, as a supervisor, she can think of multiple ways to search for a person. New staff needs more coaching using a variety of scenarios. Ms. Beatty indicated the program could develop test records based on scenarios she provides, however no record of a living or deceased person is possible
- Mr. Collins informed the committee about the Registry profile document update; a sticker indicator. The program cannot guarantee the person will place the sticker on the back of their license, so the indicator is “Sticker: Mailed” or “Sticker:” near the top of the document

Department of Revenue Data

- OPOs continue to run into issues if the license and registry do not match; it is source of family opposition
- Need to stress in communications and education efforts to talk to your family and share your decision

- The Registry no longer has the option to send a message to a loved one due to lack of utilization
- Committee recommended the Department continue to monitor and report to the committee for now

Donate Life Missouri Team/Donate Life Missouri Facebook Page

- Tabled

Missouri State Fair Education Initiative

- Mr. Collins reported the program is considering the \$3,500 sponsorship level that includes approximately 300,000 printed copies, live announcements every day, banner at a major event, booth, etc.
- An air conditioned building is preferred; booth needs to be manned and looking at 6 hour shifts
- Volunteer needs and schedule will be released; partners will help recruit volunteers and staff

Action Items

Action Items	Person(s) Responsible	Deadline
OPO Call Center Staff Training scenarios to Ian Collins	Lori Clark	Undetermined
OPO Call Center Staff Training development	Ian Collins & Virginia Beatty	Undetermined
State Fair Volunteer Needs & Shift Schedule	Ian Collins	February 2023
Annual Symbol Report to Committee	Gina Wisch & Virginia Beatty	September 2023

GOOD OF THE ORDER (Informational & Actionable)

Closing Comments/Thoughts/Suggestions

- Budget reports will become read only reports; upload partner and fiscal reports two weeks before each meeting
- Everyone is responsible for reading handouts/reports and preparing questions in advance of each meeting
- Add a sharing hour component after each meeting beginning in December. This will provide the opportunity to learn more about each of our roles, professional goals, and build stronger relationships making it easier to have tough conversations
- Everyone thanked Mr. Lee for a great job chairing his first GODAC meeting
- Ms. Diane Brockmeier is retiring as the President/CEO of MAT and moving to Kansas City to be near her daughter who is expecting a child in mid-January
- Mr. Lee announced that he will be the next President/CEO of MAT and his first day is January 2, 2023. He is humbled and honored to serve in that role and will continue to serve on GODAC
- Ms. Beatty suggested setting the 2023 meeting schedule. After discussion, it was determined that quarterly meetings would be good, there is a need to be flexible and to recognize that not everyone will be able to attend every meeting, and avoid the months of March, April, and May because of Donate Life Month; all agreed. February meeting will be virtual and have an alternate date too. The second meeting location will be either Kansas City or Jefferson City and vice-versa for meeting three. The last meeting in 2023 will be in Jefferson City

Action Items

Action Items	Person(s) Responsible	Deadline
Host Site, Snacks and Beverages	Laurie Hines	Next Meeting
Post 2023 Meeting Scheduled on Agenda	Kevin Lee & Virginia Betty	Next Meeting

NEXT MEETING (Informational & Actionable)

Agenda/Logistics

- Agenda Items:
 - Donate Life America Team
 - Donate Life Missouri Facebook Page
 - Committee Appointments, Set & Tabled Agenda Items
 - Bylaws
 - SRTR Website Navigation (Data)
 - New CMS Regulations & Performance Metrics
- Next face-to-face meeting will be in early December at the Missouri Kidney Program office

Action Items

Action Items	Person(s) Responsible	Deadline
Doodle Poll and Meeting Location Coordination	Virginia Beatty	October

Adjourn (Informational)

Meeting adjourned at 12:17 pm Kevin Lee

Approved: December 8, 2012 as Amended

GODAC Meeting 9.9.2022

Partner Reports/Updates

Discussion Summary

- The University of Missouri strongly encouraged market based pay increases, so Missouri Kidney Program staff received increases based on that criteria. The program is asking for additional general revenue funding to cover payroll costs. This is the first time such a request will be made and is pending
- Ms. Hines and Ms. Beatty will be working with Health Literacy Missouri to enhance the My Kidney Transplant Workbook to make it more accessible; MAT is willing to assist
- Ms. Hines and Ms. Clark are on the End Stage Renal Disease Treatment Choices Learning Collaborative (ESRDTC), which aims to increase kidney transplants and reduce kidney discard rates. The collaborative is about communicating better, collaborating more, and inviting and listening to donor families and recipients about how to do better
- MoKP applied for a \$50K grant with Delta Dental. Dialysis center social workers indicate that oral health issues impede transplants. MoKP is working to obtain actual oral health requirements from Missouri Transplant Hospitals. MAT's Foundation will share their 10-year history of oral health funding to help estimate oral health needs. If awarded and successful after the pilot year, MoKP will move forward with securing permanent funding
- Federally Qualified Health Centers in the St. Louis, Kansas City, Northern Missouri and Central Missouri areas are committed to participate if the grant is awarded
- An executive order requires Fresenius Dialysis Centers and others to have a 30% patient referral rate for transplant. The mechanism to regulate and assure compliance is unknown. CareDx and others are working to sell their platforms to for-profit dialysis centers. The Federal Department of Justice has sued Fresenius for unethical and illegal dialysis practices in other countries
- Life Savers Rally is November 8 in Kansas City; an in-person event about organ donation
- The Kansas University Mentor Study results will be available six months to a year from now; results should indicate if mentoring an individual as they go through the transplant process improves health outcomes
- Ms. Simaitis inquired about the increase of age limit noted in Ms. Jan Finn's August email. Ms. Clark replied this is an example of how tissue donation evolves and changes over time based on the needs of surgeons
- Midwest Transplant Network data report is for their entire donor service area, next report will be Missouri only data. Ms. Clark, Mr. Lee and Ms. Beatty will set up a report for Missouri specific data on a shared platform
- MTN Family Services participated in a simulation center to improve family conversations
- The Midwest Donor Care Unit opened September 1 and welcomed several donors. The family care room is named after Ryan Grace, a child organ donor
- Brain dead donor is insensitive when talking about the Donor Care Unit. A cardiac death (DCD) donor is managed at the hospital and not the care unit. Ms. Clark will ask their communications team for appropriate language
- Ms. Hines will be speaking at the National Kidney Walk in Columbia, Missouri including how to enroll in the donor registry. Mr. Collins will provide material with a QR code that links to the Missouri registry
- Ms. Hines inquired about the minority data presented in May by Mr. Lee; the African-American population in Missouri is significantly lower than the data reported. Mr. Lee explained that the thirty-six percent of the donors approached in the St. Louis hospitals are African-American and live in their service area (parts of Mo., Il. and Ar.)
- Ms. Hines will pursue how to address health equity/inequity around organ donation and the minority population; Mr. Lee encouraged everyone to collaborate

- MAT is in their six-week strategic planning process and health equity is part of that discussion; Mr. Lee is going to suggest at the Board of Director's meeting on September 12 to narrow that focus to kidney health since it adversely impacts the black community
- End stage renal disease is a huge issue in the United States
- Mr. Lee noted that fatty liver disease will become a huge U.S. issue over the next ten years
- Health equity, health education, better engagement are all areas that need to be addressed
- Generally, black families travel in larger community groups and transplant hospital visitation policies need to become more equitable
- Missouri Hospital Association's Health Equity Council is a group of rural and metro hospitals. Ms. Hines will serve on the Council. The focus will be inconsistencies in Covid visitation policies
- Ms. Ellen K. Barnidge, Ph.D., M.P.H, is Interim Dean of the St. Louis University School of Public Health and Social Justice, and serves on the MAT Foundation Board. She may be a resource to all as we address health equity (<https://www.slu.edu/public-health-social-justice/faculty/barnidge-ellen.php>)
- MAT has identified their biggest opportunity to save more lives in increasing authorization for non-first person authorization (FPA) among black families. Actions taken include dual approach, timing, and language consistency. Actions are resulting in higher authorization rates and more lives saved through transplant
- An environmental factor that impacts the number of potential organ donors and authorization for non-FPA is gun violence. As gun violence increases, more individuals pass, and in the black communities, it requires MAT to approach family matriarchs, usually mothers who experienced negative treatment with health care facilities, to trust you to take care of their loved one
- Data is available for referral by race at every level of the recovery/transplant process. Eligible referral has two categories, standard criteria donors and extended criteria donors. The latter includes anyone over the age of 50. Ms. Hines and Ms. Beatty will meet with MAT's Business Intelligent Team about available data
- An updated report for MAT is available on the Box site

GODAC Meeting <<Insert Date>>

Mid-America Transplant

National Minority Donor Awareness Month

August is currently recognized as National Minority Donor Awareness Month. This recognition stems from National Minority Donor Awareness Week, which was founded in 1996 by the National Minority Organ Tissue Transplant Education Program to bring heightened awareness to donation and transplantation in multicultural communities – focusing primarily on African American, Hispanic, Asian/Pacific Islander and Native American communities. MT will utilize participation in these events to bring continued awareness to the community regarding donation and transplantation.

- 107th Pentecostal Assemblies of the World July 31st – August 6th
- Urban Back to School Expo – August 6th
- Annie Malone Family Fest – August 13th
- West Side Missionary Baptist Church Facebook Live – August 13th

Candlelight Memorial

Springfield, Missouri

- Campbell United Methodist Church - September 10th

Jonesboro, AR

- Location TBD – November 5th

Celebrate Life 5K Run/Walk

- Forest Park – October 9th

Donate Life Day at the Ballpark

- St. Louis Cardinals – Busch Stadium on August 14th
- Springfield Cardinals – Hammond Field on September 9th