



Governor’s Organ Donation Advisory Committee Minutes

DATE: 12.1.2020 | WebEx Meeting



Note taker (s): Virginia Beatty
Attendees: Deb Simaitis, Joan Keiser, Phil Duncan, Virginia Beatty, Laurie Hines, Kenny Kovacs, Kim Harbur, Lori Clark, Rachel Allen, Shelly Wehmeyer, Laura Beckmann, Jake Buxton, Gina Wisch, Michala Stoker, Daniel Bogle, Steve Cramer, Sandra Hentges
Called by: Peter Nicastro, Chairperson
Called to order at: 9:05 A.M.

Welcome, Introductions, Agenda Approval and Minute Approval

Ms. Nicastro called the meeting to order. Roll call taken as individuals joined the call. Kim Harbur needed to leave meeting early, without objection; High School Education Project moved from Unfinished Business to follow the Gift of Life Partner Update.

Review of corrections submitted for September 18, 2020 meeting minutes.

- First bullet under Mid-America Transplant/Team Missouri, page two, modified by adding “our” before “ICU”, adding “awaiting” after “ICU”, changed “recovering” to “recovery” and deleted “from transplants.”
- Second bullet under Missouri Kidney Program (MoKP), page two, modified by deleting “Chronic” before “Kidney,” adding “Disease” after “Kidney” and adding the definition of “ECHO” as a second sentence; “ECHO is an acronym for Extension for Community Health Outcomes.”

September minutes approved with corrections. Ms. Beatty will accept the edits and make the minutes available.

Reporting of Officers/Committees

Chairperson Report

- Committee Appointments. No update from Mr. Nicastro. No update from the Department. Ms. Beatty reported that the Executive branch’s focus and priority is the COVID response. Mr. Nicastro will follow up with Ms. Simaitis to determine contact information for the Boards and Commission office. Mr. Nicastro inquired about applicants. Ms. Beatty indicated she is aware of those who contacted the Department about appointments, including Michala Stoker, Kenny Kovacs, and Lori Kramer-Clark.

Dashboard and Financial Trend Updates

- Mr. Nicastro reviewed the Donor Fund Cash Flow table and balance graph. The fund balance as of October 31, 2020 was \$513,787.30, a 1.23 years’ worth of expenses vs. cash on hand. Mr. Nicastro opened the floor for questions. No questions raised.
- Ms. Hines recommends increasing enthusiasm of obtaining an organ donor plate and recommended asking transplant hospital executive staff and transplant surgeons to sign up for an organ donor plate.
- Mr. Nicastro reported on the Dashboard.
 - Financial contribution rate was 9.1% of transactions for August through October 2020; an 8.9% increase from August. Contribution rate reflects the number of individuals applying for a driver license or non-driver identification card who choose to contribute \$1 to the Organ Donor Program Fund.
 - Partner events with partners are down due to effects from COVID-19.
 - Consent registration trend continues to climb. The report reflects individuals 18 years of age and older. Vital records process monthly. On average, the registry grows by 367 people each day compared to 415 people per day a year ago.
 - Monitoring of youth enrollment will continue on the dashboard. Enrollment down significantly from the previous report. Youth move to the adult report on their 18th birthdate and some remove themselves from the Registry. Research to determine if youth data is available as a percentage of all youth driver license or non-driver license applications.
 - No Registry down time to report. Registry now provides an electronic process to report issues and phone numbers for emergency after business hours support.

Secretarial Report

- No financial report to share this month. Personnel service costs are lower than budgeted as staff is spending 20-30 hours a week on COVID response. This shift in responsibilities will likely continue through February 2021.

Partner Updates

Saving Sight

- Concluded observance of eye donation month in November. The theme was a community of compassion. Activities included sending videos of donor families and recipients sharing their donation/transplant experiences to hospital staff. Hospitals are grateful for streamlining of processes; making the donation process easier for them.
- Giving Tuesday twenty-hour stream-a-thon is today, December 1, on the organization's Facebook page. Recipients, donor families, and staff members are sharing their experiences about donation.
- New products in Bonfire store. Designs are in honor of eye donation month. Information on Facebook page.
- Saving Sight continues to navigate through frequent COVID changes, consuming time and resources. Most staff continue to work from home.

Mid-America Transplant/Team Missouri

- Representative not available to give report.

Midwest Transplant Network (MTN)

- MTN has seen an increase in overall referrals for organ and tissue donation and COVID deferrals; for 2020, MTN recovered over 300 organ donors and pursues all lifesaving opportunities given, even if only one organ is viable.
- November 11 was the Donor and Recovery Care Unit groundbreaking. Facility expected to open in mid-2022.
- Continue with Share Life Campaign. Celebrated National Donor Sabbath in November. MTN reached out to over 30 different faith communities, conducted interviews, and put together a video-package with all faith leaders together and separate. Faith videos are available on MTN's YouTube channel.
- T-shirt store open for license offices to purchase. They can wear them on Fridays. Orders are up.
- Releasing 2021 calendar and should go out to partners next week.
- CMS measures passed two weeks ago and waiting on adoption of measures. If adopted, reporting starts in 2022. There are three tiers in the new measures and MTN and MAT are in the top tier of all proposed CMS measures. MTN is supportive of the CMS measures.
 - Committee members and Gift of Life look forward to the adoption of the CMS measures. Increase in organs for transplant and accountability of low performing procurement organizations is expected.
- New website launches in two weeks; development was a yearlong process. Please view once live.

Missouri Kidney Program (MoKP)

- Transportation subsidy efforts continue for dialysis patients who are pending and/or COVID-19 positive so that they can still receive dialysis treatment.
- Kidney Disease ECHOs is in the fourth month of the second year. There is great participation.
- Finishing Medicare Part D enrollment for MoKP participants.

Gift of Life (GOL)

- Completed 500-classroom presentations for the 2019-2020 school year; usually complete 600. Lower numbers are due to COVID-19. Most presentations for 2020-2021 are virtual and the goal is to reach 250-classrooms.
- Virtual options make programming more marketable.
- The St. Louis program is moving slowly, currently working with the CAPS program. Students will go back into their school to implement education outreach.
- The mentoring program is working with 35 hospitals nationwide. Mentor training finished in November and mentors are ready once referrals begin. The program stays in touch with the hospitals every six weeks. Patients and mentors can be in different locations. Organ type is the base criteria for matching patients and mentors.
- Andy Donnelly, twelve-year mentor program manager, has a stage 4 cancer diagnosis. Staff are dividing his duties to assist him during this difficult time and we ask that you keep him in your thoughts.
- Actively searching for a permanent Executive Director. The interim director has been in that role for two and a half years. The goal is to have an Executive Director hired by February 2021.

Department of Revenue

- There are 589 active donor plates on file.
- Dollar donation collected for FY2020 was \$125,644; approximately an 11% increase over FY2019. Over the past five years, we have experienced a small increase in contributions of one-to-two percent, so the FY2020 increase is significant. The FY2020 contribution increase may be due to the increased number of transactions related to the Real ID Act. DOR anticipates above average transactions in FY2021 as people seek to get their Real ID prior to the October 2021 deadline; originally, the deadline was October 2020.
- It usually takes three business days between the issuance of a temporary license to the printing and mailing of a permanent license. The contracted factory has a three-business day requirement to print and mail the documents to patrons. The turn-a-round is dependent upon the day received by the factory. A small percentage of applications require DOR review delaying information to the factory; usually resolved within seven business days.

- Currently distributing updated Real ID posters to airports and exam sites. There was no change to the symbol information on the posters; that information remains the same.
- Majority of folks who were unable to renew during the total shut down have renewed.
- A new hardware refresh occurred statewide within the last two months.
- There is a new temporary license document; it is now a half-sheet with a tear off making it easier to carry than the previous temporary license. Donor symbol information is on the temporary license along with other indicators.
- All contracted local license offices are open again.
- The donor sticker only applies if the individual chooses to opt out of the symbol when applying for a license. Individuals need to register and request the sticker separately.
- The Department of Health and Senior Services does periodically receive requests and asks for a paper [or online] enrollment form from the individual so they can document the sticker request for accountability and program documentation. Staff mail the instruction letter that contains the sticker to the individual.
- Medical alert on the driver license is effective summer 2021. Necessary changes to DOR systems and cards are under development. There will be a small symbol on the front of the license with descriptive text up to 12 characters. June 1, 2021 is the implementation date.

Department of Conservation

- Mr. Nicastro thanked the Department of Conservation for their partnership. Mr. Buxton noted he is excited about the partnership, is excited to serve, and to let him know what updates are needed from Conservation.
- Mr. Buxton announced his personal connection to organ donation, as his sister-in-law is a lung recipient.
- Mr. Buxton will check into the number of clicks from the online hunting and fishing license to the Registry.

Department of Elementary & Secondary Education (DESE)

- Laura Beckmann reported the following:
 - CDC healthy school grants (3) are keeping DESE busy.
 - DESE is developing professional tools and resources for dissemination for Healthy School Development, Whole Child Approach. DESE has already released multiple tools and resources and continues in this effort.
 - Founded in 1943, the Association for Supervision and Curriculum Development (ASCD, <http://www.ascd.org/about-ascd.aspx>) is a nonprofit, nonpartisan membership organization that develops programs, products, and services essential to the way educators learn, teach, and lead. The ASCD highlighted Missouri as one of the top states working on the whole child approach.
 - DESE launched a new web site that deals with COVID-19 related specific priorities <https://dese.mo.gov/communications/coronavirus-covid-19-information>.
 - DESE teacher of the year is a physical education teacher who was on Good Morning America today.
 - Pushing communication strategies around COVID-19 including mask wearing, social distancing, etc. Everyone needs to be pushing out the same message and hopes everyone on the call will take the opportunity to do so.
- Ms. Wehmeyer reported that the fall leadership conference, while virtual, was extremely successful.

Action Items:

Share known committee applicant list with committee
 Research youth data reporting options
 Research clicks to Registry from Online
 Hunting/Fishing License Application

Person Responsible:

Virginia Beatty
 Rachel Allen
 Jake Buxton

Deadline:

Prior to Next Meeting
 Prior to Next Meeting
 Prior to Next Meeting

Unfinished Business

High School Education Project Update

- Learn Life Savers has had it challenges due to the pandemic; volunteer training and committee reaching out to school boards in the fall has been delayed.
- Committee members met in November. A “thinking of you” style video with basic information is under development and Ms. Harbur thanked Ms. Nicole Asquith with Midwest Transplant Network, Ms. Allen and Ms. Beatty for their suggestions. The 55-second video will post to their YouTube channel for viewing. Team captains are compiling their contact lists with a plan to send the video out in January to board secretaries and district curriculum directors. Luke Harbur created the edgy video that matches the Learn Life Savers online program.
- The committee meets again in December to assess the environment and determine what actions to take next.

2021 Donor Family Recognition (DFR) Update

- The planning committee began meeting in September. The April 13, 2021 event will be virtual. The platform will be Zoom or similar platform to host various networking activities and a program similar to years past; speakers, pictures of donors, reading of names, etc.

- Last year was a non-live event and this year's goal is to have a live or simulated live event.
- Donate Life America announced the 2021 Donate Life Month theme will remain the same as 2020. Therefore, reuse of last year's certificate design and invite quotes will occur.
- Plans are underway for a delivered package for families that RSVP and contents beyond a letter, certificate, proclamation, and a donor family pin is dependent upon the number of RSVP's received.
- Participation in virtual events is up and partners expect an increase in participation for the DFR event; perhaps as many as 1,000.
- Mailing of invitation letters will be in January.
- The chair usually handles securing the proclamation. Ms. Beatty needs to get the data to Mr. Nicastro.

Keep Hope Alive

- Little to no participation over the past year. The link is still on the DHSS site under organ donor.
- Ms. Allen placed a link on the new website under publications/videos after Mr. Nicastro brought it to the program's attention that he could not find it on the new site.
- Mr. Nicastro is uncertain how to get to the video when you land on the new home page. Ms. Beatty indicated that in the future the program would investigate how to make that more prominent.
- The priority right now is not consolidating training reports and sending those out to the Committee or website updates; the current priority is COVID-19.

New Business

2021 Legislative Session

- Mr. Bogle noted the prefilling starts today, December 1, and that we may see the reintroduction of previously filed legislation this session. In recent years, there has been a backlog of anatomical gift legislation including the Minority Organ Donor Month resolution. After multiple attempts, that resolution passed in 2020.
- Mr. Bogle indicated that if the Committee has any issue that they want to put forward either this year or next year to communicate this through Ms. Beatty. None heard.
- Mr. Bogle asked for the opinion of the Committee on previously filed legislation or subject matter that may be proposed in the future:
 - Death Penalty & Anatomical Gifts: Changes to the death penalty would require the administration of the death penalty in Missouri to be by gas or lethal injection in a manner that allows consenting inmates to make an anatomical gift possible. The representative that filed the legislation has term-limited out; however, it is possible for reintroduction of the legislation by another representative.
 - Mr. Nicastro indicated that Jan Finn, CEO of Midwest Transplant Network, spoke against this bill.
 - Mr. Kovacs mentioned that the proposed legislation is problematic and that the bill sponsor did not consult organ procurement agencies. Saving Sight is not in favor of such a bill.
 - Procurement agencies cannot move forward with recovery of organs and tissues of inmates due to the health risks factors that are possible within the jail system stated Ms. Stoker.
 - Mr. Nicastro indicated that it would serve Missouri well if this legislation is not reintroduce.
 - Prohibit Anatomical Gifts of Aborted Fetal Tissue (Rep. Kelley)
 - Need to consult with partners.
 - Living Organ Donor Support Act (Colorado) became law in 2018 with an effective date of January 1, 2020. Missouri has not seen such a bill to date. Mr. Bogle is collecting preliminary feedback on the Colorado law. He inquired of the Committee if such a law would be problematic in Missouri.
 - Assisting living kidney and liver donors by granting up to ten days of paid leave if their employer chooses to participate. To be eligible, employees would have to make less than \$80,000 annually and work either part-time or full-time.
 - If company opts in, to receive an income tax credit equal to 35% of the employer's expenses incurred as a result of giving an employee up to 10 working days of paid time off.
 - Law allows carrying the tax credit forward for up to five years.
 - American Transplant Foundation supported the bill.
 - Mr. Nicastro inquired if the bill had bipartisan support. Mr. Bogle indicated the House sponsor was a Democrat and the Senate sponsor was a Republican. To determine if the bill had full bipartisanship requires additional research.
 - Ms. Hines with the Missouri Kidney Program indicated the Living Donor Protection Act passed in Missouri during the 2020 legislative session and asked the Committee if there are plans to build upon that momentum. The Colorado bill offers companies a tax break, if they opt in, for the one or two employees

they may become living donors. The bill would have no to minimal fiscal impact to the State of Missouri should it be presented in Missouri. The challenge, she indicated, is that both state and federal employees get 30 days of paid leave for being a living donor and there is no type of compensation for state or federal governments. Corporations, in her opinion, are better suited to absorb the cost of a paid leave program more than governments. Otherwise, Ms. Hines does not see any harm if such a bill passes in Missouri.

- Zero fiscal impact is an unrealistic goal, as DOR is unlikely to submit a zero fiscal impact response.
- If the committee pursues such a bill in the 2021 legislative session, the Department would have between now and mid-March to secure a sponsor. Most bills introduced in March do not get very far unless prioritized by the Governor's office. However, if the Committee wants to pursue drafting recommendations for future legislative session that is also a possibility.
- If a Representative or Senator files and introduces the bill early in the 2021 legislative session, the Department will have a very short window to respond to the fiscal impact of such a bill. Pre-filing of bills gives the Department a few weeks to respond. Once the legislative session is in full swing, a couple of days is typical.
- The Colorado bill estimated a cost of \$114K for one fiscal year; not an insurmountable amount. Missouri costs need to be calculated.
- To date, Mr. Bogle is unaware that the same or a similar bill passed in other states.
- Ms. Hines, as a member of a National Living Donor Board, stated the board, while interested in the Living Organ Donor Support Act, is much more interested in living donor protections vs. incentivizing programs/laws.
- Mr. Nicastro stated the Living Organ Donor Support Act it is an interesting idea for the Committee to continue discussing and prioritize it, along with other topics, in which the Committee has an interest.
- Mr. Bogle will consolidate the Colorado law information and send to Ms. Beatty to distribute to the Committee.
- Mr. Nicastro thanked Mr. Bogle and Ms. Beatty for keeping track of bills that may affect organ, eye and tissue donation in the state of Missouri, including what might be. Mr. Nicastro asked Ms. Beatty to send out alerts to the Committee and its' partners as feedback is needed. Ms. Beatty agreed and asked Committee members and partners to alert her and Mr. Bogle of any legislation of which they may be aware or learn about and not wait for solicitation of information. Mr. Nicastro agreed.

Moving Forward

- Mr. Nicastro requested information a couple of months ago to help determine what was of interest to the Committee and partners. He indicated there are two common ways to look at that. One is a SWOT analysis and the other a Start Stop Continue analysis.
- Mr. Nicastro received a few responses; Mrs. Harbur, Ms. Beatty, Mr. Lee, and Ms. Finn.
- Mr. Nicastro opened the floor to others to provide feedback that may not have had the opportunity before and asked, strategically, what should Committee and program priorities be.
 - Highlight/promote license plate availability (opportunity-MoKP)
 - Continue to go virtual with events (strength-Saving Sight); make sure we are doing what is right for the community due to COVID
 - Agree with virtual events (MoKP) and supporting live event means making a larger contribution, as there is not much of a role with virtual events. In addition, supporting organizations are not as visible at virtual events
 - Be more involved with virtual and live events (Saving Sight)
 - Use breakout rooms hosted by individual partners in donor family recognition (start-DHSS); interesting, Families need to tell their story, this might be an opportunity for them to share
 - Diversity, breadth and depth of the group, along with updates (strength-MoKP).
 - Committee vacancies (weakness-MoKP)
 - Too many people RSVP'ing for DFR program – potential of 1,000 people (threat-Mr. Nicastro, MoKP agrees)
 - Technology challenges for virtual events – rural areas especially (threat – MoKP and Mr. Nicastro)
 - Partner reports as part of group meetings are inspiring/information (continue)
 - Ms. Simaitis stated Committee is getting stagnate, new members needed. Need new ideas. Need to reach out to legislators and get the Governor to make appointments. GODAC needs a shakeup. (threat – Ms. Simaitis and Mr. Duncan)
- Mr. Nicastro will integrate today's comments with those previously submitted and discuss at the next meeting.

Recognition of Service:

- Today’s meeting is the last official meeting for Ms. Joan Keiser as she is leaving her hospital position at the end of this year; leaving a vacancy for the hospital representative position. Mr. Nicastro congratulated Ms. Keiser on her retirement.
- Mr. Nicastro indicated the Committee has a recognition award thanking Ms. Keiser for her service as a member of the committee and as the chairperson for two years. Since the item is in the Jefferson City office, Mr. Nicastro asked Ms. Keiser to join us at the next meeting for the presentation.

Action Items:

Learn Life Savers YouTube Link
 Living Donor Support Act Prioritization
 Legislative Alerts for Feedback

Person Responsible:

Virginia Beatty
 Committee Members
 Virginia Beatty &
 Committee Members

Deadline:

Prior to Next Meeting
 Next Meeting
 As needed

Proclamation Data
 Consolidate Moving Forward analysis

Virginia Beatty
 Peter Nicastro

February 2021
 Prior to Next Meeting

Good of the Order**Closing Comments/Thoughts**

- Mr. Nicastro thanked all of the partners for joining and contributing to the meeting. The Committee is always interested and wants to bring everyone’s perspective and knowledge to the table.
- Next meeting will be virtual and held in February 2021. Ms. Beatty will send out a poll for a meeting date.
- Mr. Nicastro noted his appreciation of the Department of Health’s Vaccine Plan.

Next Meeting**Agenda/Logistics (December 2020)**

- Ms. Beatty will send out a poll for the next meeting date, agenda, and location of the next meeting.

Action Items:

Provide updates.
 Develop agenda.
 Issue meeting poll.
 Send out agenda and handouts.

Person Responsible:

Partner Representatives and
 Committee members
 Mr. Nicastro & Ms. Beatty
 Ms. Beatty
 Ms. Beatty

Deadline:

Next Meeting
 November 2020
 November 2020
 Prior to Next Meeting

Adjourn

Meeting adjourned at 11:18 A.M.

Peter Nicastro, Chairperson

Approved 2.24.2021