



Governor’s Organ Donation Advisory Committee Minutes

DATE: 12-5-19 | Conference Call



Note taker (s): Rachel Allen
Attendees: Jim Pruitt, Virginia Beatty, Rachel Allen
 By Phone: Deb Simaitis, Peter Nicastro, Joan Keiser, Phil Duncan, Lisa Britt, Nicole Kellen, Kim Harbur, Laurie Hines, Steve Cramer, Shelly Wehmeyer, Michala Stoker, Kevin Lee
Called by: Joan Keiser
Called to order at: 1:12 pm

Welcome, Introductions, Agenda Approval and Minute Approval

Ms. Keiser called the meeting to order and gave the welcome. Rachel Allen was introduced. Ms. Beatty completed roll call. Ms. Simaitis proposed to add Department of Conservation to the agenda. The agenda was approved as amended. The September 17, 2019 meeting minutes were approved with the following correction: change to second paragraph, removal of “st” after the date in “August.”

Action Items:	Person Responsible:	Deadline:
Minutes updated and posted	Virginia Beatty	Next Meeting

Reporting of Officers/Committees

Chair Report

- Appointment Update: Ms. Keiser inquired of appointment information. No change in GODAC applications status. Ms. Keiser states any seeking reappointment/appointment should follow up with the Governor’s Boards and Commissions Office and/or their state Senator.
- A member asked why the Bylaws were included in the meeting material. Ms. Keiser indicated it is good to have them at meetings and the annual review is approaching. Ms. Keiser asked if Ms. Simaitis and Mr. Nicastro could review the Bylaws and report at the next Committee meeting. Both agreed.

Dashboard and Financial Trend Updates

- Mr. Nicastro reported the fund’s November balance as \$580,457. No questions. Mr. Nicastro provided the dashboard report and included contribution rates for the three month period ending September 30 at 6.92%, up from the last report when it was 6.5%, and down from the June’s report. Consent Enrollment for adults is 3.17 million and continues to rise slowly. An average of 415 people per day were added over the past 12 months; progressively down from three years ago. No unscheduled registry downtime reported.
- Ms. Harbur inquired if a consent trend, for teens, is available; she would like to track if the online high school education program has any effect on teens and their registration to be on the state registry. Mr. Nicastro stated he will start to think about different categories for a potential report. Ms. Beatty added that an age distribution by county report is currently available and includes under 14 and 15-17 years of age categories.

Secretarial Report

- Staff changes: The Health Program Representative II position has been filled by Rachel Allen. Ms. Beatty introduced Ms. Allen to the committee, noting her first day as November 1. She will be working with the Donor Family Recognition Day and the Donor Registry System. The Secretarial position is still vacant and plans are to fill the position.
- FY20 Financial Report: Revenue for the period of July thru October 31 is about 45% of projected income; \$117,510.63 (revenue) of \$261,298.00 (projected). The Health Program Representative II position vacancy created some cost savings. It was decided to not transfer money out from the kidney collaborative line item; this money has been set aside for product printing. Reduced the “Other (Materials, Initiatives, Media)” line item by \$13,000. Remaining balance in line item will only be spent depending on the fund balance. Travel expenses were reduced due to not going to the national conference. State Data Center Charges for the first few months were cheaper than expected. Software budget reduced due to not updating current licensing because of new system development. Details are available on the budget handout.

Action Items:	Person Responsible:	Deadline:
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Unfinished Business

2020 Donor Family Recognition Update

- Ms. Allen reported that the Donor Family Recognition subcommittee has begun planning the 2020 event set for Tuesday, April 14. The theme is Garden of Life. Missouri Department of Conservation has agreed to donate sapling trees and Baker Creek Heirloom Seed Company agreed to donate wild flower seed packets for each donor family that attends. Speakers will include Mr. Nicastro; other speakers are still being recruited/confirmed.

High School Education Project Update

- Ms. Harbur reported the High School Education Project subcommittee has been developing training packets and training of volunteers is expected to start in the summer. The project is on track for subcommittee members to start presenting to School Boards in March.

Online Registration Discussion

- Mr. Nicastro requested to discuss online registrations and how to make that an easier process. Ms. Beatty informed the Committee the new donor registry system (DRS) is still on target for a mid-January release. Mr. Nicastro recommended review of other state registries. Discussion held. Ms. Beatty conveyed that several other state registries were reviewed prior to the request for proposal (RFP) release and that the new system will be mobile friendly.

Annual Report Update

- Ms. Beatty thanked members and partners for articles and stories that were submitted. Staff is working to have the report completed and released by mid-January.

Strategic Plan Discussion

- Strategic planning remains tabled. It was suggested the subject be removed from future agenda's. Mr. Duncan suggested the topic be tabled until the next face-to-face meeting. No dissension.

Action Items:

Provide updates at next meeting.

Person Responsible:

Rachel Allen, Kim Harbur,
Virginia Beatty, and Kevin
Lee

Deadline:

Next Meeting

Send Informed Consent language to members

Virginia Beatty

ASAP

Add Strategic Planning to Agenda

Joan Keiser

Next Face-to-Face Meeting

New Business

Donor Registry System Modernization

- Ms. Beatty stated the new system is still on target for a mid-January release. Discussion held. Ms. Beatty was asked by the Committee to send out information on informed consent.

Legislative Report

- Mr. Cramer reported numerous pieces of legislation have been pre-filed. Affecting organ donation is Senate Bill 551, sponsored by Senator Whelan, which prohibits discrimination in insurance, making it illegal to not insure individuals solely based on being an organ donor. Bill discussed. Ms. Beatty will begin sending out legislative updates.

Partnerships

- Ms. Keiser asked if there was any other new business. Ms. Simaitis stated that the Missouri Department of Conservation has made a lot of effort in the last year to highlight organ donation. Ms. Simaitis moved to invite the Department of Conservation to become a partner with GODAC. Motion carried. The Chair asked for a roll call vote. Motion passed with four members voting in favor and one abstaining. Ms. Beatty will draft the letter and Ms. Keiser and Ms. Simaitis to review. Once finalized, Ms. Beatty will route for approval, obtain signatures and mail. Mid-America Transplant suggested the Committee consider reorganizing their agenda so that as partnerships grow, meetings can be better managed. Discussion about meeting order held. Ms. Keiser will consider the suggestions.

Action Items:

Legislative Updates

Person Responsible:

Virginia Beatty

Deadline:

ASAP

Extend Invitation to Missouri Department of
Conservation (draft, review, route, send)

Joan Keiser, Deb Simaitis,
Virginia Beatty

ASAP

Partner Updates

Department of Secondary and Elementary Education

- The Department's liaison was unable to attend the meeting. No report.

Saving Sight

- Saving Sight reported they recognized eye donation month by sharing new donor family stories throughout the month of November. Staff has also spent time in hospitals personally thanking hospital staff that assist in the eye donation process. The organization recently launched an apparel fundraiser.

Mid-America Transplant/Team Missouri

- Mr. Lee with Mid-America Transplant reported they are having a record year to date with 713 organ donors. Increased outreach to donor families continues. Increased participation in candlelight memorials seen. Increase of 15-20% in local St. Louis workshops participation noted. Partner, Heartlinks Grief Center, hosted first workshop where donor families and recipients participated together. The foundation has welcomed the 196th guest to Family House. A family from Three Rivers, Mo., who had a two-year-old on the heart transplant wait list, moved into the Family House in October. The child's condition worsened and on October 29, nurses and medical staff asked the family to prepare to say their final goodbyes. On October 31, another family said yes to donation and the two-year-old received a heart. Mr. Lee stated that Family House and the work of our organizations save lives. Mid-America Transplant is looking for a new location to expand the house so more families that are waiting for the call or who are recovering from a transplant can benefit from the proximity to the St. Louis transplant centers in the future. Currently the house can support 10 families and Mid-America Transplant wants to expand that to 20 families. SSM Health Saint Louis University Hospital completed their one-hundredth organ transplant.

Missouri Kidney Program (MoKP)

- Ms. Hines communicated they formally invited Ms. Beatty to be a new partner and serve on the Missouri Kidney Advisory Council Partner Group. She accepted the invitation. Missouri Kidney Program has formed the Missouri Kidney Collaborative and are in the final stages of completing a transplant workbook for patients who are ready for kidney transplant. Ms. Beatty is a part of that Collaborative. The workbook is a place for patients to journal as they travel through their transplant journey. MoKP has been working over the last year to influence Missouri transplant center hospitals to provide paid leave for employees who choose living donation. The University of Missouri System, all four campuses and the Hospital, now offers paid leave for living donors and bone marrow donors after approval by the Board last week. The program is currently working with St. Louis University Hospital to adopt the same or similar policy. The National Donor Alliance is forming to represent the interest of living organ donors nationwide and in the process of determining their project focus. Ms. Hines, a living donor, was asked to be a part of that alliance. She has accepted the invitation. Representative J. Nadler introduced the Living Donor Protection Act of 2019 to Congress earlier this year (116th Congress, 1st Session).

Midwest Transplant Network

- Midwest Transplant Network reported they were recently named corporate sponsor of the year with KCTV. They participated in a blood drive this fall with University of Missouri where they handed out 500 t-shirts to students and community members and were able to verify 250 people on the registry. Midwest Transplant Network will be participating in the Rose Parade again this year with the Flora Graph of Nicole Sawyer. The annual Legacy Walk is being moved to the month of June and will become an evening event. The location will change to the national WWI Museum in Kansas City and will focus on donors and bringing the community together.

Gift of Life (GOL)

- Ms. Harbur reported Life Savers program is in 21 counties in Missouri and Kansas, expecting to reach 31,000 during the 2019-20 public school year. The Life Savers Rally was held in September with 650 students from 21 schools in attendance. Kansas City now has a part-time educator, where the part-time educator position in St. Louis is currently vacant and recruitment continues. The GOL board is searching for a permanent organization CEO. The 2020 focus for GOL is to mentor more kidney patients and their families, strategic and succession planning, updating their systems and databases, and filling vacancies.

Department of Revenue (DOR)

- The Department's liaison was unable to attend the meeting. No report. Ms. Simaitis thanked DOR for the message "Save Lives. Register to be An Organ Donor" on the driver license information they send out.

Next Meeting		
Action Items: Provide updates. Agenda/Logistics: Send out poll to determine March meeting date	Person Responsible: Partner Representatives Virginia Beatty	Deadline: Next Meeting ASAP
Adjourn		
Meeting adjourned at 3:01 p.m.	Joan Keiser, Chair	

Approved as Amended at March 2, 2020 Meeting