Governor’s Organ Donation Advisory Committee Minutes
November 29, 2017

Note taker(s): Debra Gholson
Attendees: Virginia Beatty, Valerie Volkart, Steve Cramer, Sandy Hentges, Jim Pruitt
By phone: Joan Keiser, Peter Nicastro, Deb Simaitis
Called by: Deb Simaitis, Chair
Called to order at: 10:35 am

Welcome, Introductions
Ms. Beatty announced those in attendance. Ms. Deb Simaitis called the meeting to order at 10:35 am.

The Boards and Commissions Task Force Report Discussion

- Mr. Nicastro asked “What constitutes a quorum today?” Ms. Beatty asked if the Committee was going to vote today or if the meeting was called for discussion? Ms. Simaitis said this is just a discussion. Ms. Beatty read the bylaws to the group which states that a quorum is a majority of members of the Committee exempting any who have submitted their resignation to the Chair person.

- Ms. Simaitis announced she called the meeting as requested by Peter Nicastro and in accordance with Committee Bylaws. The Boards and Commissions Task Force Report was sent to the committee on October 31, 2017, and pages nine and ten of the report pertain to the Governor’s Organ Donation Advisory Committee. The members interpreted the report to be the task force’s decision to consolidate several Department of Health and Senior Services boards into one board that would contain nine members. However, that perception has changed dramatically since Ms. Simaitis’ meeting with Dr. Randall Williams on November 28, 2017. Ms. Simaitis shared with the Committee that Daniel Bogle, Director, Office of Governmental Policy and Legislation, was also present for the meeting. The Governor’s Task Force recommendation was discussed and Ms. Simaitis expressed the Committee’s concerns with the report. Dr. Williams and Mr. Bogle did not interpret the report in the same way. They assured Ms. Simaitis that GODAC will not be eliminated, and that the only change that will occur, if legislation passes, is that the Department Director (Dr. Williams) will make the appointments instead of the Governor. Dr. Williams provided assurances that he will stay on top of the appointments. The discussion continued with increasing the number of members from ten, and Dr. Williams said he would consider it. Ms. Simaitis stated that she left the meeting feeling reassured that the Committee will be even stronger if these changes occur. She believes that Dr. Williams and Mr. Bogle are both very much in favor of organ and tissue donation.

- Ms. Keiser asked about the Committee having ten members and not an odd number. She is pleased to hear that Dr. Williams and Mr. Bogle support organ and tissue donation. Ms. Beatty responded to the “ten member” question: The Committee comes under the Department and if the Director makes the appointments, as a state employee, Ms. Beatty would not have voting rights, so that would leave the Committee nine voting members. If changes occur, the Bylaws will need to be modified.

- Mr. Nicastro read and commented on pages nine and ten of the report. He expressed his thoughts on the other services that he believes are supported by general funds and do not have a board. One of GODAC’s important purposes is to track what Missouri residents donate separate from general revenue. He also expressed that at this time each person on the Committee serves at the pleasure of the Governor; if the Director takes over it will be at his pleasure, and he will be able to remove, as well as appoint members. Committee members reminded him that is true if the appointments remain as part of the Governor’s duties. Mr. Nicastro feels the Committee is being demoted and that organ, eye and tissue donation is being seen as less important. Ms. Simaitis responded that Dr. Williams takes this very seriously and he takes great responsibility of the duty that will be his. He is hopeful that legislation to implement the change will pass this year and that he will vet possible members very carefully.

- Ms. Simaitis continued reviewing the information she shared with Dr. Williams; how the Committee
does not cost the state any money and the Committee is funded strictly by donations. She explained that state statutes would have to change if the Committee were to be supported by general revenue funds.

- Mr. Nicastro expressed his concern that the Committee is not up-to-date and it is not just the current Governor that is at fault, but it has not been stable for some time. Ms. Simaitis shared Dr. Williams’ assurances that this will not be the case if he is tasked with making appointments.

- Ms. Beatty commented that the GODAC is an advisory committee that makes recommendations, not final decisions. She also mentioned that appointments should be much quicker, making GODAC a more stable committee. She asked Ms. Simaitis if Dr. Williams was going to replace everyone or if he has a plan in place. Ms. Simaitis replied that she asked him if he was considering adding or replacing members, and she asked that he not remove all members at the same time to ensure continuity and smooth transitions. Dr. Williams did not give her any indication either way.

- Mr. Nicastro recapped what he understands from the conversation and asked about trust. Ms. Simaitis stated that she believes Dr. Williams is very serious and trust should not be an issue.

- Ms. Beatty commented that we have to keep in mind that the changes have not passed at this time and asked members to consider that Dr. Williams is being proactive and trying to think about how he will make the appointments. This says a lot about his dedication to the Committee and to the other committees he will be responsible for if legislation passes. In the meantime she recommends the Committee continue business as usual.

- Ms. Hentges thanked Ms. Simaitis for her approach to Dr. Williams. She was very informative, educational, kind spirited, and served as a very positive extension of the Committee.

- Ms. Simaitis reported that Dr. Williams asked if it would be possible to find out how many of the 61,000 employees are listed in the Registry. Dr. Williams also stated that the Governor wants Missouri to lead the nation in all things and Dr. Williams feels it is important to be able to say that a certain percentage of Missouri employees are registered donors. Ms. Simaitis shared with Dr. Williams that she did not agree that this was the way to go and shared her concerns of privacy issues.

- Mr. Nicastro and Ms. Beatty both commented that they have concerns about confidentiality related to Dr. Williams’ idea. A survey could be conducted; however, Ms. Beatty believes that this should not be pursued at this time. She further stated, should Dr. Williams decide to pursue this idea he would submit a formal request to the program. Mr. Nicastro suggested we discuss at the December 6, 2017 meeting.

- Mr. Nicastro told the story about Governor Blunt announcing he was in the Registry. Ms. Beatty stated the program looked up his information because he called and wanted to know if he was registered. How he chose to share that information was his choice, not the programs. Privacy is a top priority for the Registry.

- Ms. Simaitis also suggested the Committee discuss this matter further at the December 6, 2017, regularly scheduled meeting.

- Ms. Beatty commented that since Dr. Williams has not made a formal request and until he does she believes that this should not be discussed further. Ms. Simaitis agrees. Ms. Simaitis thanked everyone for participating and adjourned the meeting.

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**Adjourn**

Meeting Adjourned at 11:13 am

Chair, Deb Simaitis

Approved as amended 3/9/2018 meeting.