



Governor’s Organ Donation Advisory Committee Minutes

March 9, 2018

Note taker(s): Debra Gholson
Attendees: Virginia Beatty, Valerie Volkart, Sandy Hentges, Jim Pruitt
By phone: Joan Keiser, Peter Nicastro, Deb Simaitis, Sarah Dolezal, Laurie Hines, Kenny Kovacs, Gina Wisch, Steve Cookson, Phil Duncan, Jan Finn
Called by: Deb Simaitis, Chair
Called to order at: 1:05 pm

Welcome, Introductions

Ms. Beatty announced those in attendance. Ms. Deb Simaitis called the meeting to order at 1:05 pm, and welcomed everyone. Agenda adjusted to allow one hour and twenty minutes for Unfinished Business; agenda approved as adjusted.

The Boards and Commissions Task Force and HB 2548 Recommendations

Unfinished Business

- Ms. Simaitis gave a brief overview and history of HB 2548. Representative Cookson stated that he would speak to the House Chairman concerning this bill. Ms. Simaitis reiterated to Rep. Cookson and the Committee that Dr. Williams and Mr. Bogle assured her that this change would not affect the Committee.
- Mr. Nicastro explained HB 2548. He said that it was possible that when Ms. Simaitis met with Dr. Williams and was assured this bill would not eliminate the Committee that changes had been made after that meeting, therefore Dr. Williams may not be aware of these changes. HB 2548 is 122 pages long so Mr. Nicastro shared the changes that affect the Committee; section 192.2700 of the bill. He said the bill creates the Health and Senior Services Board and makes no provision for the Organ Donor Advisory Committee in section nine. In section two, one member of the Organ Donor Advisory Committee is assigned to the Board of Health and Senior Services. Section three accommodates a subcommittee; the Board can appoint a subcommittee for organ and tissue donation but it is not a requirement. Mr. Nicastro continued and noted the organ donor fund and how the bill transfers the fund responsibility from the Committee to the Board. The same for the license plates. Reviewing section 194.300 through 194.303 RSMo, the Organ Donor Advisory Committee is struck out and replaced with the Board of Health and Senior Services. Mr. Nicastro explained that this bill will in fact eliminate the Organ Donation Advisory Committee and it is the discretion of the Board of Health and Senior Services to appoint a subcommittee.
- Mr. Nicastro reviewed the Organ Donation Advisory Committee Dissolution Situation Background Analysis Recommendation (SBAR) with the Committee, explaining the information he felt was important and to be highlighted. He described the fact that HB 2548 eliminates the Committee in favor of a seven person Board of Health and Senior Services. He gave a brief background of HB 2548. Mr. Nicastro included the history and accomplishments of the Committee, and that the members serve voluntarily and without compensation, costing the state of Missouri nothing. The recommendation of the Committee is to speak collectively to the General Assembly to oppose the passage of the sections mentioned in the SBAR.
- Ms. Simaitis asked if there were any edits to the SBAR. Ms. Simaitis recommended that under “Analysis” to change the word “donation” to “contributions” in the last sentence. Under “Recommendations” change “program” to “greater organ and tissue donor committee” in the second to last sentence. Ms. Keiser stated that the last sentence in the first paragraph under “Background” does not read correctly and Mr. Nicastro suggested removing the word “that” and the Committee agreed.
- Ms. Simaitis asked for a motion to approve the SBAR as edited. Mr. Nicastro motioned to present with the mentioned edits to the Director of the Department of Health and Senior Services. Seconded

by Phil Duncan. All approved with noted changes. Virginia Beatty abstained from the vote.

- Representative Cookson is in support of this SBAR, as he made clear on the call prior to disconnecting.
- Representative Cookson invited Ms. Simaitis to call his office and set up an appointment and he would arrange for her to meet with Speaker of the House, Lt. Governor Parson, and Representatives Taylor and Britton. He will let Ms. Simaitis know when these meetings are arranged.
- Ms. Hentges and Ms. Beatty reminded everyone that these meetings and any contact with your representatives must be as an individual not as a member of GODAC, until the SBAR is approved.
- Jan Finn joined the call and Ms. Simaitis brought her up to date. Ms. Finn agreed with the SBAR.
- Ms. Simaitis asked for notification when the oversight committee meets on HB 2548. She inquired about the meeting with Dr. Williams that she requested at the Monday GODAC meeting, and Ms. Hentges reported that the request was with Mr. Cramer.
- Ms. Simaitis and Mr. Nicastro asked if it was possible to request the testimony of DHSS on HB 2548. Ms. Hentges has asked Mr. Cramer and she will report her findings. Mr. Pruitt said that he read the minutes and did not find any testimony documented.
- Next meeting will be in June and officer elections held, so prepare your nominations. Please complete the poll for the date.
- Ms. Beatty will make corrections to the SBAR and email the Committee the corrected version, and then will forward the SBAR through appropriate channels for approval.

Adjourn

Meeting Adjourned at 2:02 pm

Chair, Deb Simaitis

Organ Donation Advisory Committee Dissolution

Bureau of Cancer and Chronic Disease Control

March 9, 2018

Situation

GODAC has, since its inception, had its membership by gubernatorial appointment. Following his election, the Governor appointed a task force by executive order to eliminate a number of gubernatorial appointments. The subsequent bill introduced in the Missouri House will eliminate the Committee in favor of a seven-person Board of Health and Senior Services.

Background

On October 31, a task force appointed by the Governor by Executive Order 17-11 and led by the Lieutenant Governor Parson released a report calling for the reorganizing of Missouri's many boards and commissions. Among the recommendations of the task force were the elimination of the Organ Donation Advisory Committee (p. 10, *ff.*) The report further recommended an advisory subcommittee under a new Health and Senior Services Board for the Organ Donation Advisory Committee, and boasted of eliminating 110 gubernatorial appointments, including those of GODAC.

On February 22, Rep. Jered Taylor (R – Nixa) introduced HB 2548, which substantially implements the recommendations of the task force. The germane language of the bill to the Organ Donation Advisory Committee eliminates the committee in its entirety, and transfers all of its functions to the new Health and Senior Services Board, which would have one member currently on the Committee, by an undescribed mechanism of appointment. If the bill were to become law, the Committee would cease to exist on August 28, the effective date for non-emergency, non-appropriation bills.

Analysis

The Organ Donation Advisory Committee was formed in 1996 with the 1995 passage of HB 178. In its 22 years, the Committee has assisted the Department in the creation of the Organ Donor registry, the conversion of that registry from a paper basis to a computerized database, the transition of the original intent version of the registry with a consent registry, the registration of 3.7 million Missourians, the addition of a check off box benefitting the fund on the individual income tax form and the subsequent elimination of its sunset, the creation of free continuing education for first responders on the value of their intervention in donation, the institution of an annual donation education day at the Capitol, and most recently, the foundation of an increasingly successful recognition program for donor families.

While entitled to expenses from the fund, no member has claimed expenses within the memory of all currently serving. Rather, all the board members are and have been volunteers and worked free of charge to the fund. The only member who is paid is the representative of the Department. In addition to meetings of the Committee, members perform many other tasks in support of the larger organ, eye, and tissue donation community. Moreover, the community itself is engaged with the committee. Committee meetings are open to the public, of course, but the meetings themselves and their agenda have always fostered the input and engagement of the larger donation community. The Committee's strategic plan, accordingly, lays a framework for the entire Community, not just for the Committee and the Program. The elimination of the Committee would destroy this avenue for the community to meet, confer and work together, a critical function that costs the state *nothing*.

Separately, the task report conflated the situation of the Organ Donation Advisory Committee with the Missouri Brain Injury Advisory Council, the Genetic Advisory Committee, and the Missouri Palliative Care and Quality of Life Interdisciplinary Council, each of which are funded by general revenue, comparing these with 16 funds *funded by general revenue* which do not have a board. The Organ Donation committee is the only one of these with its own fund. One of the foremost responsibilities of the Committee is to recommend priorities in the expenditures from the organ donor program fund, in addition to its education, awareness and reporting functions. The Committee serves a vital function in safeguarding the contributions of Missourians, apart from General Revenue, which makes it unlike the three other committees.

Recommendation

The Department should approve the Committee to act and speak collectively to the General Assembly simply to preserve itself and oppose the passage of the sections above as part of the larger reshuffle of boards and commissions.

We believe that the functions of the Committee cannot be effectively and so exhaustively performed by a smaller committee with less experience in organ, eye, and tissue donation and many additional responsibilities, as is proposed in HB 2548. Mere silence from the Department and the Committee is likely to be interpreted as an acceptance of the language in the bill, to the detriment of the program, and the elimination of the Committee as an avenue and mechanism for continuous improvement of the greater organ and tissue donor community. As such, we personally and collectively oppose it.