**MASSACHUSETTS RARE DISEASE ADVISORY COUNCIL (RDAC)**

**Steering Committee Meeting Minutes**

Thursday, October 17, 2024

**MEETING TIME 10:30 am – 11:30 am**

Approved October 31, 2024

**Welcome:** Dr Tierney, committee chair, welcomed all to the RDAC steering committee meeting on Thursday, October 17th 2024.

He then conducted a roll call for attendance and called the meeting to order at 10:35 after establishing a quorum.

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| Member | Present |
| Representative Jay Livingstone | Yes |
| Jenn McNary | Yes |
| Dr. David Miller | No |
| Tai Pasquini | Yes |
| Dr. Ryan Thompson | Joined at 11:01 |
| Dr. Dylan Tierney | Yes |

Dr. Tierney then asked if all received the minutes from the last steering committee meeting on August 15th. All noted. He then asked if there were any edits or revisions. No one had any edits or revisions. He then asked for a motion to accept the minutes as presented. Rep. Livingstone motioned to accept the minutes, T Paquini seconded the motion. Dr. Tierney then conducted a roll call vote to accept the minutes.

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| Member | Accept |
| Representative Jay Livingstone | Yes |
| Jenn McNary | Yes |
| Dr. David Miller | NA |
| Tai Pasquini | Yes |
| Dr. Ryan Thompson | NA |
| Dr. Dylan Tierney | Yes |

**Chair update:** Dr Tierney opened the meeting with a discussion about RDAC operations and DPH oversight of the council. D Tierney stated that he has been meeting with DPH leadership and DPH general council and had some updates. He started by stating that the legal council reviewed our legislative language and believe that the words “*There shall be a rare disease advisory council within the department*,” means that the RDAC is a council of DPH and under the direction and control of DPH. He added that the commissioner’s office would be taking a more active role in setting agendas and priorities with mutual DPH and RDAC priorities in mind. He plans to meeting with the BIDLS leadership, more specifically, Dawn Fukuda, about the council on a regular basis. Dawn Fukuda will be meeting with the commissioner on a regular basis and will be the liaison between the commissioner and the council chair.

He then added that the general council let him know that our subcommittees and working groups must follow open meeting law. They also stated that any subcommittee/work group of the council must have a defined odd number of members, a defined goal, and must be voted on by the full council. They had some specific questions about the legislative subcommittee and suggested that Thera Meehan, track any bills relevant to the RDAC. He added that DPH cannot comment about any legislation. As a council under the direct guidance of the commissioner, the council could not comment about the pros or cons of any specific legislation. He stated that DPH wants to have control over any information specific to legislation. He noted that the RDAC needed to develop a specific structure for how they will be involved in any specific legislation and he will bring it back to
DPH for approval on moving forward or not.

**Rep Livingstone:** asked if the RDAC wanted to pursue something and the commissioner didn’t agree, does the commissioner have veto power.

**D Tierney:** stated that he did not know the answer to that question but he would bring it back to DPH.

**J McNary:** stated that this change was deeply concerning. If it’s true that the commissioner has veto powers over the RDAC work including agendas and recommendations, it feels like we have no autonomy and therefore, no voice. If this is the case, I would recommend that we look at another structure. Other states have different structures that all autonomy of their council.

**Rep Livingstone:** stated that it may be challenging if the RDAC wants to change it’s structure but the commissioner doesn’t agree, not much will probably happen.

**D Tierney:** stated that this all seemed to evolve after the RDAC discussions and recommendations related to newborn screening. As you all know, we did not have a clear understanding of the newborn screening program when we started looking into it. At first, we thought it was run by UMass, then we realized that UMass only conducted the technical part of the program and under the guidance of the Newborn Screening Advisory Committee. This committee reports directly to the commissioner. Once we made recommendations for the newborn screening program, DPH became involved and concerned that one DPH council was giving recommendations to another DPH committee.

**J McNary:** stated that many of the issues and concerns of the rare disease community may be related to a program or policy that fall under the direction of DPH. Does this mean that we can’t make recommendations on anything under the direction or guidance of DPH?

**D Tierney:** reiterated that he would do his best to represent the council and would be the liaison to the commissioner. He stated that this change in direction was all new to him as well.

**J McNary:** stated that she felt that most all topics of concern to the RDAC may involve auditing DPH and if we can’t do that, then we just become a rubber stamp for the commissioner’s agenda.

**Rep Livingstone:** stated that he would like us to push back on the “control” line with the commissioner. He added that sometimes he is asked to discuss issues related to legislation that he was actually involved in writing. Although, I always have to be careful about what I say, there is a need for me to be involved in the discussions. He then stated that he believes the structure of the legislation was intended to involve several experts in the field with the intent of improving the lives of those living with a rare disease through recommendations to the governor, the legislature and DPH.

If the commissioner has veto power, I am confident that the other council members will not embrace this new direction.

**J McNary:** Can’t we just proceed as we have been and if there is a recommendation that involves DPH, D Tierney could just abstain from voting.

**Rep Livingstone:** stated that he knows of other committees that operate that way

**T Pasquini:** Asked how these changes will affect how we do things. For example, how we collect data, write reports, etc. I’m very concerned about how this will slow up our work. I think we will be stymied by this process. Look how long it’s taken to get our new appointments.

I can also speak to the legislative workgroup as I was on it. The workgroup’s intent was to just assess legislation that may be out there and how it may impact the rare disease community. I feel strongly that we need to look at all aspects of a topic and if the commissioner doesn’t want us to look at some specific side of an issue, we have all the information.

**D Tierney:** I’m working on how I can best represent the commissioner.

**T Pasquini:** What is a realistic next step? If we want to look at a different structure, how do we go about that?

**J McNary:** It seems that we were allowed to conduct business since our inception and all of this just arose after we came up with recommendations for the newborn screening program. This seems like a knee jerk reaction.

**D Tierney:** stated that he didn’t think that the issue was about developing recommendations but more about one DPH council monitoring another DPH committee.

**J Livingstone:** stated that it would be really helpful to hear directly from the commissioner. I would like this group to meet with the commissioner.

**D Tierney:** stated that he would bring this request back to the commissioner

**T Pasquini:** stated that she understood the advocacy piece and that the council is charged with conducting research to meet the legislative mandates and if DPH is involved in this, it will make things a lot more complicated.

**D Tierney:** then stated that he would reach out to the commissioner to see if he could attend our next meeting but he would like to move onto the next agenda item. Newborn Screening Recommendations for our annual report. He stated that DPH reviewed the recommendations of the RDAC and had some edits. He then shared some slides to explain the changes.

After sharing the first slide, he explained that DPH would like the line highlighted to be removed. He stated that the new maternal health law that was recently passed, requires the committee to meet at least twice per year that we didn’t need to put that in our recommendations. He also state that DPH would like the line in red to be removed also as the committee has the ability to meet virtually and they didn’t think we should put forth any recommendations that speak to the regulations for newborn screening.

**J McNary:** added that one of the most important reasons that we added this is because the committee has not met. She asked if there was any confirmation of a meeting date this fall. They have not had a regular meeting cadence and we still don’t have any indication when that will change.

**SLIDE 1**

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**D. Tierney:** Advanced the next slide (below) stating that DPH would like to take out all the language in yellow. He stated that DPH was not in favor of requiring an annual report. They do not want to add any additional burden on the committee or the program.

**SLIDE 2**

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**J McNary:** added that she felt that one of the most important reasons the this was added was because we still don’t know information about their review process, how they deal with new and emerging technologies, or why they decided to include a new disease or disorder to the pilot.

**D Tierney:** advanced to the next slide (below) and stated that DPH did not feel that we could require the sponsor of a federal RUSP packet to attend a meeting. DPH wants to remove all text that is highlighted.

He also stated that DPH was not clear about the meeting of benefits. He asked J McNary to resend her description of benefits as discussed in the NBS workgroup.

**SLIDE 3**

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**J McNary:** stated that she had created an extensive document about benefits and she would resend that to D Tierney. She reiterated that she and the workgroup spent a lot of time on this topic and she has detailed information about considering a broader definition of benefits.

**D Tierney:** then advanced to the next slide. (slide 4) He stated that this was ok as is and DPH did not have any specific changes or edits.

**SLIDE 5**

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**D Tierney:** then advanced to slide 6 (below). He explained that requiring DPH to create webinars and videos would cost money and they currently don’t have a budget for something like this. He recommended changing the language to say “Develop other modes of communication to explaining the program to the public including simplification of parental brochurre accordding to heath literacy, ADA andd plain language principles.”

He asked if all agreed with that change.

No one disagreed.

**SLIDE 6**



**SLIDE 7**

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**D Tierney:** Advanced to the final slide: slide 7. He explained that DPH did not have any issues with the recommendation.

He then noted that it was now almost 11:30. He asked if the group wanted to meet again before the next full council meeting, especially as we did not get through most of our agenda.

All agreed to meet.

**J Livingstone:** suggested picking a date while all were on the call. They you will have a specific date to go back to the commissioner.

All agreed to Thursday, October 31st

**D Tierney:** stated that he would go back to his supervisor, Dawn Fukuda and the commissioner and he would get back to all soon. He then asked for a motion to adjourn.

**T Paquini** made a motion to adjourn, **J Livingstone** seconded

**D Tierney:** Adjourned the meeting at 11:32