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

**STEERING COMMITTEE**

REMOTE MEETING:    Thursday April 17, 2025

**Meeting Time 10:30 am – 11:30 pm**

**Meeting Minutes –** Approved June 26, 2025

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**Committee Chair Dr. Dylan Tierney** welcomed all to the meeting.

He then announced that the public is welcome to join any of the RDAC meetings.  However, only guests who are on the agenda will be allowed to speak during the meeting. For all guests on this call, he asked that they please make sure that their video was turned off and their audio was on mute. He also asked that people please refrain from using the chat function.

He then conducted a roll call vote to establish a quorum

**Roll Call**

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|  | Member | present |
| 1 | Dr Christelle El Achkar | X |
| 2 | Representative Jay Livingstone | X |
| 3 | Jenn McNary | - |
| 4 | Tai Pasquini | X |
| 5 | Dr. Ryan Thompson | Joined at 10:40 |
| 6 | Dr. Dylan Tierney | X |

A quorum was established and the meeting was called to order at 10:34

**DT** then asked all had received the meeting minutes from the last steering committee meeting on 2/27/25. All confirmed. He then asked for a motion to vote to accept the minutes as presented; Rep. Livingstone motioned and T Pasquini seconded.

**DT** then conducted a roll call vote to accept the minutes as presented.

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|  | **Member** | **Approved** |
| 1 | Dr Christelle El Achkar | abstained |
| 2 | Representative Jay Livingstone | X |
| 3 | Jenn McNary | - |
| 4 | Tai Pasquini | X |
| 5 | Dr. Ryan Thompson | X |
| 6 | Dr. Dylan Tierney | X |

**DT** let all know that he was going to walk through the RDAC workstreams for 2025. He proceeded with an update about medical nutrition. He let all know that the policy subcommittee was going to take the lead on medical nutrition. They were reviewing the language of the 2022-23 federal bill sponsored by Congressman Jim McGovern. He also let all know that Rep McKenna, who is on the policy subcommittee, will be talking with Health Policy Commission to see if we can get a report on the status of medical nutrition in Massachusetts. We really don’t know the issues. We have heard that there are insurance challenges but it would be very helpful to have data on the issue.

**DT** then asked Rep. Livingstone if he thought that there was anything the RDAC could do to support the federal work being done by Congressman McGovern.

**Rep Livingstone** – suggested that it may be helpful to reach out to other RDACs so see if they would support the federal bill. He didn’t think that it would be a good use of time to wordsmith the language of the old bill as it will go through many iterations before being presented for a vote.

**T Pasquini** offered the following link : MNEACostAnalysisFactSheet062821.pdf stating that it gave the facts related to cost analysis.

**DT –** asked the committee what they thought the report should include?

**T Pasquini** asked if we would be looking at outcomes? Or are we looking at what is covered and what gaps may exist?

**Rep Livingstone** stated that the federal bill was looking at how many people get access to medical nutrition and how many don’t get what they need. He suggested that we would need some outcome data to be persuasive to the legislature. They usually want to know, how will lives improve with the expansion of medical nutrition.

**DT** – then gave an update on the pediatric to adult transitions of care discussion. He let all know that he had talked with Andrew Dwyer, who has done a lot of work in this area. He let all know that Andrew stated that there was a lot of evidence on the standard of care as it related to the transition from pediatrics to adult care for those with a rare disease. He added that A Dwyer was going to take a first draft of recommendations and bring it to the committee for review.

**R Thompson** asked if the RDAC made recommendations related to transitions of care, where would they go. He also added that recommendations would be very helpful for institutions and providers.

**DT –** added that the recommendations would go in our annual report which would go to the governor, the legislature and the Department of Public Health.

**R Thompson** follow up by stating that we needed to be sensitive to rural providers when we make our recommendations.

**T Pasquini –** stated that there are many discussions going on now in the Center of Excellence (CoE) smeeting at her institution. Thinking about expectations would be helpful. She stated that some of the CoE doctors are often overwhelmed and have trouble responding to all the calls..

**DT –** brought up the fact that in the last full council meeting, one of the members offered that doctors should not be allowed to deny a patient.

**R Thompson –** suggested that if our recommendations are supported by DPH, it would be a good thing. All may not follow the recommendations but some is better than none.

**T Pasquini** suggested that it would be really helpful if patients were allowed to see out of network providers if the current team was not able to handle the patient’s needs. She suggested the Minnesota passed a similar provision. She feels that many issues are a result of in-network vs out-of-network providers.

**DT –** stated that the RDACs charge is to provide recommendations based on our research.

**R Thompson –** suggested that we hear from providers or pathways that is going transitions well. Can we show what excellence might look like.

**DT –** stated that we would look into getting speakers at the next full council meeting. A Dwyer is working on that.

**R Thompson** – Supported that thought of a panel to hear from groups, even if they are not rare disease patients.

**DT –** stated that we would move on to the economic burden study. He asked T Pasquini if she could provide a one-pager on the scope of the project.

**T Pasquini** stated that she would work on the scope summary one page document.

**DT –** suggested that he would meet with DPH leadership once he has the summary document.

He then stated that our next priority was a discussion about an information/referral line or an ombudsman type service. He wasn’t quite sure where the group wanted to go with this.

**T Pasquini** asked if anyone knew of any projects were being cancelled or cancelled due ot the loss of federal funding.

**Rep Livingstone-** stated that the legislature is looking at this. He stated that the funding cuts seem to be impacting staffing verses programs. He also noted that Massachusetts relies less on federal funding than other states. He also noted that MassHealth is the largest part of the state budget. The federal government has not taken clear action on cuts.

The Massachusetts budget is roughly $62B and $16B is federal reimbursement, $12-14B is healthcare. We have $8.3B in rainy day funds, which is second to the highest amount of any other state in the country but some of the gaps may be too large to make up.

**T Pasquini** asked if it was the right time for the RDAC to be pushing some of the priorities.

**Rep Livingstone –** states that it appears that right now, the cuts seem to be coming as a result of the closing of regional offices. He states that he hasn’t seen individual program cuts at this point.

**DT –** stated that with the moving sands under our feet maybe we should hold off on the ombudsman idea.

**R Thompson** – stated that although there is a huge need, it may not be the best time to pursue this idea right now.

**DT –** the last topic is related to a registry. The commissioner had an interest in this topic so we will work on getting a meeting with the commissioner to discuss this.

He then deferred the rest of the meeting to Tai to share her thoughts on a council engagement survey. She stated that the point would be to learn more about the members and their interest on doing work outside of the full council meetings. She then asked if anyone had any questions or comments.

**Rep Livingstone –** added that he thought the survey was great.

**R Thompson –** also added that he thought it was great.

**DT –** asked about sending the survey out next week so that we can give feedback at the next full council meeting. He then asked for a motion to adjourn.

**Rep Livingstone** made a motion to adjourn, **T Pasquini** seconded.

**DT –** adjourned the meeting at 11:33.