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

**STEERING COMMITTEE**

**Meeting Minutes**

REMOTE MEETING:    Thursday February 27, 2025

**Meeting Time 10:30 am – 11:30 pm**

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Dr. Dylan Tierney welcomed all to the meeting, then conducted an attendance roll call to establish a quorum.

**Roll Call**

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

A quorum was established so Dr. Tierney called the meeting to order at 10:38 am.

D Tierney then asked all if they received the minutes from the last steering committee meeting on 12/19/24. All acknowledged that they received and reviewed the minutes. D Tierney then asked if there were any edits or corrections to the minutes. No one responded so he then asked if there was a motion to accept the minutes as presented.

**Rep. Livingstone** made a motion to accept the minutes, **T Pasquini** seconded.

**D Tierney** took a roll call vote.

**Roll Call Vote to approve minutes from 12.19.24 Steering Committee**

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|  | Member | Approved |
| 1 | Representative Jay Livingstone | X |
| 2 | Tai Pasquini | X |
| 3 | Dr. Ryan Thompson | X |
| 4 | Dr. Dylan Tierney | X |

**The minutes were approved.**

**D Tierney** reviewed the agenda. Then moved to the first agenda item. He asked for discussion and review of the presentation on finding a helpline or ombudsman for the rare disease community. He reviewed the presentation from 211 and MassOptions at our last full council meeting. He asked what the committee thought we should do next.

**T Pasquini** asked if we knew how many people called in and how many people actually got services. She stated that it would be nice to know how many people were not able to get what they needed. She stated that she would like to see what kinds of resources they have and where the gaps may be for the rare community.

**D Tierney** stated that he was left with some uncertainty after the presentation about what services exist in their database for the rare disease community. He then mentioned that the director of 211 offered to add any resources the council felt were important for the rare community. He let all know that the director also asked if someone could train the 211 staff on rare disease so they were prepared to answer calls appropriately.

**Rep Livingstone** added that there was another resource we may want to look into, Healthcare for All. He then stated that he understood that there were two primary problems for the rare disease community. First is the diagnosis odyssey and then once there is a rare disease diagnosis, often times the needs are no different than people with many other conditions. The resources needed may be common to many other people. He stated that he was unclear how to help resource the diagnosis odyssey issue.

**T Pasquini** stated that it could be helpful if a rare disease diagnosis provided access to additional services.

**R Thompson** stated that he witnessed the challenges of rare disease patients and caregivers every day. He offered a patient example stating that often times a rare disease patient and caregivers are just trying to get through each day and are often unaware of what they need, what would help or how to find help. He added that doctors like himself are often unaware of resources either. He said he often wonders what resources are actually available for his patients. He added that sometimes his patients will hire an advocate that work to find resources but if they don’t have the money to hire an advocate they are left to figure out things themselves. He stated that he has worked with the Ombudsman in the past that has been very helpful with placements and wondered if there was a similar position to help with resources it would be helpful.

**T Pasquini** wondered if the social workers at the hospital could help.

**D Tierney** suggested that maybe we start with 211 and asked what others thought.

**R Thompson** stated that it sounded like we are proposing a pilot with 211. He added that it may be a good starting point. He also suggested reaching out to MassHealth as they often work in silos. Maybe we can figure out the resources offered by MassHealth and make sure they are available in 211 database.

**T Pasquini** offered that she worries about callers not getting what they need. She suggested holding a one day summit for rare disease. Maybe the attendees can help us to better understand what needs they have. She expressed that she fears that people won’t even know to call even if we train 211 staff.

**D Tierney** stated that he wasn’t clear what data 211 actually monitored. He asked for caller and outcome information but wasn’t sure they collected that information.

He then summarized the discussion by asking if all wanted to look into this more and all agreed. He added that we would see if we could get a list of the resources they have now and see if we could identify any gaps in what is offered.

**T Pasquini** asked if there was a way to breakdown the resources into domains. For example, insurance, homecare, transportation, etc.

**D Tierney** then stated that T. Pasquini would like to talk about council engagement.

**T Pasquini** shared a word document with some suggestions on how to engage more of the council members. She realizes that time is challenging for most people on the council but maybe we could find out what their interests are and what they have time to commit to. She suggested doing a survey of members. She stated that there seems to be a handful of council members doing most of the work and unless we understand why, it will be hard to know how to encourage engagement.

**Rep Livingstone** offered that he is involved with many groups and this topic is not new. Group dynamics are always challenging. Some people may find it hard to talk in an open forum and others may dominate the discussion. He thought the survey was a good idea.

**D Tierney** asked T Pasquini if she could share her thoughts on survey questions and he would review them and bring it back to the steering committee for comments.

The next agenda item is to review our Standard Operating Agreement (SOP). D Tierney stated that we write the SOP in 2022 in the early stages of the council and thought it was a good opportunity to review them. He stated that we have had a few members that attend very few if any meetings. She we have a minimum number of meetings that member should attend?

**R Thompson** suggested that we send attendance reports to the appointing body to let them know that their appointee is not participating.

All agreed that the SOP did not need any specific updates at this time.

**D Tierney** then reviewed the plans for the full council meetings in March and May. He provided a quick update on Rare Disease Day presentations and stated that it was now 11:30. Did anyone have anything else to discuss.

**Rep Livingstone** made a motion to adjourn; T Pasquini seconded. D Tierney adjourned the meeting at 11:33.