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

**STEERING COMMITTEE**

REMOTE MEETING:    Thursday, August 17th, 2023

2:00 pm – 3:00 pm

**Meeting Minutes Approved October 19, 2023**

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**Chair Dr. Dylan Tierney welcomed all to the meeting at 2:03.**

He conducted a Roll Cal for attendance.

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| Member | Present |
| Representative Hannah Kane | x |
| Dr. Jeff Livingstone | - |
| Jenn McNary | Joined at 2:35 |
| Dr. David Miller | x |
| Michele Rhee | - |
| Dr. Ryan Thompson | Joined at 2:05 |
| Dr. Dylan Tierney | x |

**VOTE**  to approve meeting minutes from the last steering committee meeting on 6/8/23. D Tierney asked if all had reviewed the minutes. All agreed. He then asked if there were any edits or corrections. All responded no.

Rep Kane made a motion to accept the minutes as presented

D Miller seconded the motion

D Tierney took a roll call to approve the minutes.

**Roll Call Vote to approve minutes from 6.8.23 Steering Committee**

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| ***Member*** | ***Approve*** | ***Abstain*** |
| Representative Hannah Kane | x |  |
| Dr. Jeff Livingstone | NA |  |
| Jenn McNary | NA |  |
| Dr. David Miller | x |  |
| Michele Rhee | NA |  |
| Dr. Ryan Thompson | x |  |
| Dr. Dylan Tierney | x |  |

**Workgroup 1 update – D Miller** gave an update on the prevalence paper of workgroup 1. He explained that they had a workgroup meeting to review the paper. T Pasquini has been making the revisions as recommended by the workgroup. The workgroup plans to present it for approval at the September full council meeting.

**D Tierney** asked the committee for their thoughts on how to present this. He suggested that we include it in the annual report and then present it at a legislative event in February around Rare Disease Day. He asked for thoughts from the group.

**Rep Kane** stated that we should think about presenting it in early February before Rare Disease Day.

**D Tierney** agreed that it made sense to do that.

**Rep Kane** added that we were coming up on the end of the first term for council members, and we needed to think about how to show what we have done for the first three years. She stated that all appointments would be up in 2024, and members should consider whether they want to continue on the council for another term.

**D Tierney** stated that we were working with DPH about the protocols for this.

**Rep Kane** stated that reappointments may be different depending on their appointing body. She offered to reach out to the Speaker’s office to ask about this. She stated that John Walsh was the appropriate person to reach out to for the Speaker’s office and she would let Mary Lou know who to contact from the Senate President’s office.

**D Tierney** asked all to move on to discuss the agenda for the September full council meeting. He stated that we planned to have Barbara LItalien, who was the author of the Autism Report. He stated that she might be helpful for the RDAC to think about what should go into our annual report. He added that the Autism Report was developed after five years of work from an advisory committee, and it has been instrumental in changing policies and systems related to Autism in Massachusetts.

**Rep Kane** stated that the Autism Report was influential in changing policies and systems because it was strongly backed by the autism community in Massachusetts. She stated that the RDAC has not had an opportunity to hear from the public yet, and in order for a report to have an impact, it really needed public and legislative support.

**D Tierney** asked the committee what they thought about making recommendations in the annual report. What should we do about recommendations? Should we have just one for this report?

**R Thompson** asked for an example of what a recommendation would be.

**D Tierney** stated that one example might be about recommending that we establish an office of rare diseases in state government. This has been discussed in the past. Another example may be that we make a recommendation related to telehealth. He expressed that whatever recommendations we make, they must be thoughtful, actionable, measurable, and achievable.

**Rep Kane** reinforced the need to engage the public. She stated that she would not feel comfortable making recommendations without public input. She emphasized that it had nothing to do with the council's expertise; we need to ensure that the public is behind our recommendations. She stated that we should recommend what is most important to the rare disease community.

**D Tierney** stated that this was a good time to move to the next discussion about the public meeting to gather testimony from the public. He stated that we had discussed holding a virtual town hall in October. He asked what people thought about the day of the week and the time of day. What day and time would be best? Can the town hall give us enough information and feedback from the public to be able to make a recommendation by the end of the year?

**R Thompson** stated that he felt that there had been enough discussion within the council to recommend establishing an office of rare diseases. As an action-oriented council that is only advisory, it would make sense to establish an office to implement its recommendations. He stated that one of the biggest challenges in the rare disease community is that it's very general. Many diseases may only have one or a few with a specific diagnosis, so advocacy is difficult. I think we should make a recommendation that strengthens the council's work.

**Rep Kane** agreed and stated that she totally agreed with making at least one recommendation but emphasized that we also needed to consider how that recommendation would be implemented. She also stated that any recommendation would be stronger if the rare disease community supported it. She stated that the governor was very committed to the work of this council and would support any effort that allowed Massachusetts to become a leader in supporting the rare disease community. She stated that establishing an office of rare disease would take time, but she thought it was possible. There is a lot biotech companies in Massachusetts, we also have world-renowned hospitals that would support Massachusetts in becoming a leader in this area. She then stated that the timing of any recommendation was important.

**D Tierney** asked how we should proceed. Should we discuss recommendations at the next council meeting? How much internal discussion do we need? How do we get public feedback about this? Should we draft a recommendation before the October meeting and ask for the public’s feedback on this?

**Rep Kane** stated that it made sense to ask for public feedback, but we also needed to consider how our recommendation(s) would be implemented.

**J McNary** stated that over the past year, we have discussed how complicated all of this is, so I’m in full support of recommending the establishment of an office of rare diseases. The council can only do so much. If we had an office of rare diseases, that office could implement the council's recommendations. I think it’s a good idea.

**D Tierney** asked how to proceed. Do we need to develop a budget for this kind of recommendation?

**Rep Kane** stated that it would be important for the governor to include this in her budget. This is the number 1 way to show the importance of this line item. It would also be important for the commissioner of public health to support this if it was going to be in the DPH budget. It would be important for the commissioner of public health to talk to the secretary about this.

**D Tierney** stated that he would begin conversations with the commissioner’s office about this. He then shifted back to the public town hall. The town hall may be a great opportunity to let the public know our thoughts. We could gather support for our recommendations at the public meeting.

If we were to hold this meeting in October, what day of the week and what time of day? The meeting will be virtual, but when would we get the highest participation?

**J McNary** stated that she felt an evening or a Saturday would be best. For the people in the rare disease community that she knows, during the week would be hard.

**R Thompson** agreed with J McNary. The meeting should be in the evening or on a Saturday.

**D Tierney** stated that we would work on some possible dates for this meeting and would focus on a Saturday in October. He then shifted to the next agenda item-Social Media. He stated that there was an interest in the RDAC to have its own social media. It started as a way to get the survey tool out, but then it was realized that other topics or discussions of the RDAC would be helpful to put on social media. He asked the group what social media they think best for the RDAC.

**J McNary** stated that we should consider Facebook, X (Twitter), and Instagram. She stated that she thought that younger adults would go to Instagram before the others.

**D Tierney** asked how the RDAC would manage the social media accounts.

**J McNary** stated that she reached out to a social media and communications person at a biotech, and they stated that they would be willing to help us with a plan. She stated that they could also help with content.

**R Thompson** asked how we would respond to questions. He felt that this could be a very busy and challenging task.

**D Tierney** stated that we haven’t really explored the logistics, but we envisioned that the town hall would have a structured agenda. We would ask a question, and people would have a designated about to time to respond or give their feedback, but we still need to work through the logistics.

He then shifted to the next agenda item. Tracking legislation.

He stated that DPH tracked legislation but not specifically about rare diseases. That person could expand the tracking with search words related to rare disease community interest. We also need to discuss what to do with this information. DPH cannot advocate for any legislation.

**J McNary** asked if it could be an awareness tool. Could we list the bill, then summarize it and not give an opinion? It would be an opportunity to increase awareness about bills. I think we could also give people information on how to advocate for bills. Most people don’t know how to do this.

**Rep Kane** stated that it was very important for people to know how to find a bill and teach them how to advocate, but it may not be a good idea to get into posting about hearings. That would be very difficult and time-consuming.

**D Tierney** let everyone know that Massachusetts would be represented at the NORD Summit in October.

***NORD Rare Diseases & Orphan Products Breakthrough Summit*** (https://nordsummit.org/)

He then thanked everyone for the good discussions and asked for a motion to adjourn.

**Rep Kane** made a motion to adjourn.

**J McNary** seconded

**D Tierney adjourned the meeting at 3:00 pm**