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

**STEERING COMMITTEE**

REMOTE MEETING:    Thursday, December 15, 2022, 10:30-11:30 AM

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Meeting Minutes

Approved 2.16.23

**Welcome –** Dr. Dylan Tierney welcomed all to the meeting.

**Roll Call** Dr. Tierney conducted a roll call for attendance to establish a quorum.

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| Member | Present |
| Representative Hannah Kane | x |
| Dr. Jeff Livingstone | x |
| Jenn McNary | x |
| Dr. David Miller | x |
| Michele Rhee | x |
| Dr. Ryan Thompson | - |
| Dr. Dylan Tierney | x |

**Quorum-** A quorum was established. Dr. Tierney brought the meeting to order at 10:34

Dr. Tierney asked if all had received the minutes from the last meeting and had any edits or revisions. No one replied. Dr. Tierney asked if he could get a motion to vote to accept the meeting minutes as presented.

Rep. Kane made a motion, and J. McNary made a second

Dr. Tierney conducted a Roll Call Vote to approve minutes from 11/3/22 Steering Committee.

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| ***Member*** | ***Approve*** | ***Don’t approve*** |
| Representative Hannah Kane | x |  |
| Dr. Jeff Livingstone | x |  |
| Jenn McNary | x |  |
| Dr. David Miller | x |  |
| Michele Rhee | x |  |
| Dr. Ryan Thompson | - |  |
| Dr. Dylan Tierney | x |  |

Minutes accepted.

**Review of subcommittee workgroups –** Dr. Tierney stated that all workgroups were established. Every member of the council was on at least one workgroup. Each workgroup has a chair and the groups will begin meeting in the new year.

**J. McNary –** asked about the role of the chair. How will the chairs know what their responsibilities are?

**D. Tierney –** stated that we would have a meeting with the 3 chairs on January 6th to discuss the roles and responsibilities of the chair. Each chair would have the support of Mary Lou to create agendas, take minutes and assist with logistics around meeting planning.

He also stated that we hoped that each workgroup would meet during the same months as the steering committee (every other month) and report to the full council at each meeting.

**Review of the annual report draft due to the legislature on December 31, 2022.**

**D. Tierney –** asked if everyone had received the annual report draft. All responded affirmatively. He then asked if anyone had any comments or edits.

**Rep. Kane –** Asked to include legislators in the list of members under the executive summary. She also thought it would be a good idea to add the mission statement to the executive summary. Also, stating something about how we start each full council meeting with a presenter who has been impacted by a rare disease. This is something that continues to ground the group in its mission.

In the background section, she thought it was important to add information about the cost issues that people with rare disease face.

She reviewed the list of members and stated that the appointing person for the senate should be the senate president, and the appointing person for the house should be the house speaker.

In the conclusion section, we consider holding public forums to hear from the public. We should also consider a legislative briefing to inform the legislature about our work. Keeping this council on the minds of the legislature is always a good thing.

**R. Thompson –** asked about funding opportunities. As we begin to work on the priorities, we may need some analytical work or data evaluation work. How will this be paid for? Should we look into raising funds to pay for the work?

**D. Tierney-** stated that we are looking into how to set up an account with the treasurer’s office. We had discussed a fundraising committee, but no one signed up. Mary Lou will look into how to get an account set up.

**J. Livingstone-** stated that his company often works with organizations from the rare disease community and they often have very sophisticated data sets. We should work with some of these organizations as we develop a methodology to identify what data we want and need. He also thought we should add information in our report about working with other organizations and not working in a silo. We want to collaborate and coordinate our activities with rare disease stakeholders.

**Rep. Kane** stated that it might be a good idea to add the mission statement to the conclusion as well as in the executive summary.

**J. McNary-** We should make sure that we state that we will come up with an actionable plan to help those impacted by rare diseases.

**D. Tierney –** Asked all to review the report and send any edits or comments to Mary Lou by Wed., Dec. 21st. The report is due on Dec. 31st, and we need to send it to EOHHS for prior review. We plan to submit the report for review on Friday, Dec. 23rd.

**Rep. Kane –** asked if we could cc the council members with the report is submitted so that all know that it has been submitted.

**Discussion**: Dr. Tierneystated that the legislative language refers to a rare disease plan for Massachusetts but gives no details on what the plan should include. How does the council want to define a “comprehensive rare disease plan.”

**Rep. Kane –** spoke about the plan’s goal. We want a plan that will address ways to improve the lives of those impacted by a rare disease. It may be legislation or it may be creating new policies. Massachusetts is one of the top states for healthcare related to treating rare diseases. We are a state that is very rich in biotechnology. We want to encourage innovation in developing drugs and technologies that benefit those with a rare disease. We need to think about that as we design our plan. We need to think about ways to provide guidance about how the legislature can help. The plan should be high-level so we can find ways to connect the dots. We want Massachusetts to be at the cutting edge of research and innovation for those with a rare disease. We want to encourage innovation. How do we give a voice to those impacted by a rare disease?

**D. Tierney –** let everyone know that it was now 11:28 and we needed to discuss our meeting day and time for the steering committee. Some people had a conflict so was there a better day and time for all.

**M. Rhee –** asked if we could send out a doodle poll to see people’s availability.

**D. Tierney-** Asked if 10:45 on the third Thursday worked for people. All indicated that it would work. Dr. Tierney stated that it was now 11:30, was there a motion to adjourn?

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

**J. McNary -**made a second

**D. Tierney** – stated that the meeting was adjourned at 11:33 and that Mary Lou would contact the committee to see if we could find a more agreeable time to meet.