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

**STEERING COMMITTEE**

**Meeting Minutes – Approved December 19, 2023**

REMOTE MEETING:    Thursday, October 19th, 2023

**Meeting Time 10:30 am – 11:30 am**

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**Welcome: Dr. Dylan Tierney, committee chair, welcomed all to the meeting at 10:32**

He then conducted a roll call to determine who was present.

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| Member | Present |
| Representative Hannah Kane | x |
| Dr. Jeff Livingstone | no |
| Jenn McNary | x |
| Dr. David Miller | x |
| Michele Rhee | no |
| Dr. Ryan Thompson | x |
| Dr. Dylan Tierney | x |

**VOTE**  to approve meeting minutes from the last steering committee meeting on 8/17/23.

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

**Plans for the virtual town on October 28, 2023**

The agenda was discussed. All agreed that the agenda would be as follows:

Introduction

Short remarks from Legislators present

Testimony order according to sign-up date

If time allows, we will open up testimony to all.

**Rep Kane** asked why there was a cut-off for written testimony on Oct. 25th?

All agreed to remove the cut-off and open up written testimony for two days after the event. People would be able to submit written testimony through the online registration until Monday, Oct. 30th.

**J McNary** explained that maybe they were being too cautious and optimistic. She thought that there may be too many to review.

**D Tierney** asked if it was possible to notify all registrants to let them know of the change. He also asked the group if we should go forward with the event even if we only have a small number of registrations.

**Rep Kane** and **J McNary** both agreed to go forward with the event even if it was a small number.

**D Tierney** stated that there would be a dry run on Monday, October 23rd.

**Rep Kane** stated that she had not heard that a public event like this should not require a quorum. Even though most of the council members have agreed to participate, she felt that we should go forward even if there was not a quorum.

**J McNary** agreed to move forward and stated that we should release the survey at the event. She explained that the workgroup was working on translations in Spanish, Portuguese, and Chinese. She then asked how we were handling the town hall for people who wanted translation.

**D Tierney** stated that the program would allow closed caption so people could self-select the language they wanted to be in the closed caption. He then asked if there were any other questions or comments related to the town hall. No one responded so he moved on to the next agenda item.

**Review plans for November 16, 2023 full council meeting.** He stated that we were getting to the end of the year and we needed to think about the annual report which is due at the end of the calendar year. He asked what the committee thought about not submitting any recommendations this year. As he summarized, we are still gathering information and data and we may be premature if we don’t have all the information before making a recommendation.

**J McNary** stated that after meeting with other states at the NORD Summit last week, she realized that other states that have conducted surveys, have had funds to hire a company to conduct it and summarize the answers. As an all-volunteer council where everyone has a full-time job, it’s hard to get the work done the way we would like and in the timeframe we would like.

**R Thompson** asked if we could anything learn from the other states.

**J McNary** stated that she learned that all RDACs are set up differently. It may be helpful to hear from other states about how they are managed and how they get work done.

**D Tierney** agreed that it could be helpful to hear from other states and he would reach out to a few that he met at the Summit.

**R Thompson** stated that we needed to think about other ways to get public feedback. He stated that he knew a lot of patients and families are struggling just to manage their rare disease and may not be able to go to the public event. He suggested that we reach out to advocacy groups and other medical provider groups to see if they can help.

**J McNary** added that the complex care team at MGB may be able to help. She also suggested that we think about doing some interviews with social workers and case managers who care for patients with a rare disease.

**D Tierney** added that Pennsylvania did a survey. They used a survey firm to conduct the survey and still got only a small number of respondents. Maybe we need to look at other ways to reach the estimated 7,000 patients with a rare disease who live in Massachusetts.

**R Thompson** stated that there was a new chair of the complex care group and he would reach out to him. He added that he knows firsthand that transitions from pediatric to adult care is very challenging. He will talk with the new chair and get back to the group with any thoughts from their brainstorming session.

**Rep Kane** stated that we should try to get input from both patients, advocacy groups, and social workers and case managers. If we look at the spectrum of pre-diagnosis to long-term care the spectrum to broad. We need to find a way to get input from all aspects of the continuum of care.

**J McNary** stated that in her day job, she worked with rare disease patients and families. She suggested some regional listening sessions may be another way together information.

**D Tierney** thanked the group for their thoughtful discussion. We need to think about how we may operationalize small group sessions. Although it should great, how would it get done?

**Rep Kane** stated that the first step would be to identify the groups we would like to talk to. We then need to create an interview tool and decide who would do the interviews and who would analyze the data gathered.

**R Thompson** offered to talk with his group, the complex care team, and see if they had suggestions for what questions to ask.

**D Tierney** asked if we needed to form a new workgroup to design this project. It may be more extensive if we want a qualitative review also.

**J McNary** stated that there are agencies that do this type of work. Maybe we should see if one of them would volunteer to help the RDAC as we do not have any funds to pay someone. If we could formulate the design, she would be willing to reach out to a few of those companies. She stated that this type of project would be very time-consuming and she didn’t see any RDAC member having the time to do it.

**D Tierney** stated that this was a very creative idea and we needed to work on it some more before we could present it to the larger group.

He then let everyone know that he had reached out to the communications department at DPH about using social media to promote our events and survey. They told him that we could create a FB page but someone would need to take charge of managing it.

**J McNary** askedif we could create a more robust website. She stated that Pennsylvania had a very robust website. Maybe we need to think about getting more information on our website.

**D Tierney** stated that he had communicated with DPH about tracking legislation. There was a person at DPH that tracks bills and legislation, and she would help. We need to know what we will do with this information before starting this work.

**Rep Kane** stated that the RDAC’s role was to advise. She also stated that maybe people needed some guidance on what to do with this type of information. Most people don’t know how to advocate for something that is proposed.

**D Tierney** stated that it was nearing the end of the meeting. Did anyone have anything else to discuss? No one responded.

**Rep Kane** made a motion to adjourn; **J McNary** seconded.

**Dd Tierney adjourned the meeting at 11:31**