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

**STEERING COMMITTEE**

**Meeting Minutes**

**Approved June 8, 2023**

REMOTE MEETING:    Thursday, April 27th, 2023, 10:30-11:30 AM

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**Welcome by the committee chair, Dr. Dylan Tierney at 10:35**

**Roll Call**

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| Member | Present |
| Representative Hannah Kane | Not present but Represented by Sophia Flionis |
| Dr. Jeff Livingstone | Not present |
| Jenn McNary | Not present |
| Dr. David Miller | present |
| Michele Rhee | present |
| Dr. Ryan Thompson | Joined meeting at 11:00 am |
| Dr. Dylan Tierney | present |

**D. Tierney** asked if all received the minutes from the last meeting on 2/16/23. All stated yes. He then asked if there were any edits, revisions or corrections. All stated no.

**M Rhee** made a motion to **VOTE**  to approve meeting minutes from the last steering committee meeting on 2/16/23. **D Miller** seconded the motion.

**D. Tierney took Roll Call Vote to approve minutes from 2/16/23 Steering Committee**

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

**D. Tierney** asked for a Workgroup progress update.

**D Miller** gave an update on workgroup 1. He stated that the workgroup had met twice. They have finalized the outline for a white paper to estimate the prevalence of rare diseases in Massachusetts. They have discussed the strategy for making comparisons. He stated that the group had found reliable data sets that were not specific to MA, so they needed to make comparisons and extrapolations to Massachusetts population data to determine the estimated number. He said that the group expects to have ballpark estimates, not precise numbers. The group felt that the estimates they would come up with would be sufficient for the legislature’s needs.

**D Tierney** asked if they would have confidence estimates.

**D Miller** stated yes, then asked if they needed to have confidence estimates specific to MA.

**D Tierney** stated that if the group thought they could support the confidence estimates they came up with for Massachusetts.

**D Miller** stated yes, and that the group hoped to have a draft of the white paper before the May full council meeting.

**D Tierney** thanked D. Miller and looked forward to reading the group's white paper.

**D Tierney** asked M. Rhee if should could give an update on the progress of her workgroup.

**M Rhee** stated that workgroup 2 had met twice and had just completed developing a survey tool to collect information to address the legislative charges related to social supports. She also stated that Workgroup 2 and Workgroup 3 had worked together to create one survey to meet both groups’ needs. S. Patel was working on the survey tool, and they hoped to have it ready to present at the May full council meeting. She also stated that they planned to pilot it with the workgroup members before sharing it with all.

She then stated that during her research, she wondered if working with other state RDACs to look more broadly at support services may be helpful. We don’t always know if someone has to go out of Massachusetts to access services for their rare disease and also if someone from another state comes to Massachusetts to access the services they need. A broader survey would give us more information.

She stated that the workgroup felt that they needed to stay focused on Massachusetts resources for now, but it would be nice to do a broader survey later.

**D Tierney** stated that it all made sense. Taking on such a big project would probably not be practical, but the group could address it in their report.

**M Rhee** stated that the group discussed that and settled on focusing on Massachusetts for now.

**Discussion: How to handle RDAC communication and announcement requests**

**D Tierney** stated that we had received several requests to make announcements or promote events on rare disease activities. He felt that it was not the mission of the RDAC at this time to address this. Monitoring and managing these types of tasks would be challenging at this time. He let the group know that we have reached out to our legal counsel to see if there was some standard language we could use to let everyone know that we are not able to respond to any of these types of requests at this time.

**Scheduling legislative update**

**D Tierney** then asked the group what they thought about conducting a legislative update. He reviewed that the group had planned to update the legislature at the Rare Disease Day at the statehouse, but it was canceled. Did the group have any thoughts on how to send an update to the legislature? No one responded, so D. Tierney said he would contact Rep Kane, who may have some suggestions.

**Contact data collection form for updates and communications**

**D Tierney** asked the group what they thought about collecting information from the general public to send council updates and other notifications.

**M Rhee** stated that in her experience, we needed a plan for using the data before collecting it. She didn’t feel that we had a clear plan of communicating with the public at this time, so we probably shouldn’t collect it.

**D Tierney** agreed with M Rhee; managing a communication list requires resources that we don’t have at this time and it maybe wasn’t the best use of the resource we currently have.

**M Rhee** stated that she agreed that we should devise a clear plan of what we wanted to collect and how we planned to communicate with people. Would we have a newsletter or regular communication plan?

She agreed that we should hold off on collecting information until we have a plan.

**In-person/hybrid full council meeting in September**

**D Tierney** let the group know that we have been working internally to try to figure out an in-person hybrid full council meeting for September. The logistics are complicated. He felt that no matter where we hold the in-person part, whether Boston or Western Massachusetts, there would be people that could not make the meeting in person at 9:00 am. He said that maybe we should stick to virtual meetings if we can’t get attendance numbers. He let the group know we would continue working on options for an in-person meeting.

**M Rhee** suggested talking to MassBio. She thought that they had a hybrid meeting space and that maybe they would be willing to sponsor the meeting. She said she would follow up with he contact at MassBio to see if she would get some information.

**Plans for public forums and public comment in Fall**

**D Tierney** let everyone know that we are also working on options for a public forum for the fall. While figuring out the in-person hybrid council meeting, we realized that the complexities of this type of public forum might not be feasible. Maybe a virtual town hall would be best.

The group agreed.

**D Tierney** asked Sophia if she knew how the RDAC could request funding for a meeting like this.

**S Flionis** stated that funding requests usually occurred during the legislative budget session. She also stated that sometimes, there is grant funding to support this type of event. She would look into it and get back to us.

**M Rhee** suggested that we make recommendations on communicating with the public in our annual report. We should maybe think about a communication plan before we make plans for something like this.

**D Tierney** stated that we started down this road when we were planning for Rare Disease Day. We made up a flyer to inform people about the RDAC, and there was a suggestion to collect data from people interested in the RDAC.

**M Rhee** added that it probably made sense to hold off on this until we have a plan.

**Agenda suggestions for the next full council meeting**

**D Tierney** asked the group for suggestions for speakers for the full council meeting in May. He asked if it made sense to have a speaker that could support the mission of the council or the legislative mandates of the workgroups.

**D Miller** stated that we might be spending valuable time listening to people with a rare disease at the beginning of our meetings. He stated that these people were speaking to the choir. Although it’s important and meaningful, he wondered if it was the best use of our meeting time.

**M Rhee** stated that maybe having the speakers be more directed to a topic. For example, she suggested that the speaker could talk about their challenges accessing services and supports, or some other aspect of dealing with their rare disease. She suggested that maybe just being more specific and directed would help.

**D Miller** agreed.

**M Rhee** suggested that maybe we could look at the categories of services and supports her workgroup identified as a starting point for finding speakers.

**D Tierney** stated that we have structured our meetings so that the rare disease speakers talk about their experience, but maybe we could ask the speaker to be more specific about the topic.

**M Rhee** added that we could also look to some of the patient advocacy groups that provide a range of programs and services that people may need. We could ask them to talk to the group about how they approach this topic. We should also be broad in our approach. We should include private, public, and government in our approach.

She thinks it's important to understand the tradeoffs that people need to make to access the services they need.

**Dr. Tierney** asked if anyone had any other ideas for speakers.

**R Thompson** added that he likes listening to the rare disease speakers at the beginning of every full council meeting. He also thinks we can learn from many unsung heroes in our communities. He can think of a neurologist in western Massachusetts who cares for one of his patients. This provider goes over and above for his patient. Maybe we can learn from him about how he accesses services and what services are not available. I know other providers in rural communities also struggle to help their patients. Maybe we could hear from some of them. I also work with MassHealth Long Term Services and Supports (MHLTSS). Maybe we could get someone from MHLTSS to speak about the services and supports they provide.

**D Tierney** asked if it made sense to have our rare disease speaker talk about their challenges accessing services and then follow up with a speaker like MHLTSS to talk about their services and support programs.

All agreed.

**D Tierney** then let people know that he had a conflict with the next steering committee meeting scheduled for June 15th. He asked the group If they could do June 8 or June 22.

**R Thompson** stated that he could not do the 22nd but could do the 8th.

**D Miller** stated that the 8th was good for him

**M Rhee** stated that she could do the 8th also.

**D Tierney** stated that the June meeting would be changed to June 8th from 10:30-11:30, and thanked all for their flexibility.

**M Rhee** made a motion to adjourn

**D Miller** made a second.

**D Tierney** adjourned the meeting at 11:30 am.