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

**STEERING COMMITTEE**

REMOTE MEETING:    Thursday June 20, 2024

**Meeting Time 10:30 am – 11:30 pm**

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Meeting Minutes (approved 8.15.24)

**Welcome**: Dr Tierney welcomed all and called the meeting to order at 10:40

He then conducted a roll call for attendance.

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| Member | Present  |
| Representative Jay Livingstone | Yes |
| Guadalupe Hayes-Mota | No |
| Jenn McNary | Yes |
| Dr. David Miller | No |
| ~~Michele Rhee~~ | NA |
| Dr. Ryan Thompson | Yes |
| Dr. Dylan Tierney | Yes |

**D Tierney** let everyone know that although we were down a few members, he would work on recruiting new members for our steering committee. He suggested that Tai Pasquini join the committee, and everyone agreed. He also let everyone know that M Rhee resigned, leaving another vacancy. He hoped that some of our new members may be interested in joining this group.

He then reviewed the agenda for the meeting and asked if everyone was able to review the minutes from the last meeting on April 11 and if anyone had any edits. All responded that they received the minutes, and no one had edits. He then asked for a motion to vote to accept the minutes as presented. J McNary made a motion to accept the minutes, and Representative Livingstone seconded. The minutes were unanimously approved.

**Roll Call Vote to approve minutes from 4.11.24 Steering Committee**

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| ***Member*** | ***Approve*** |
| Representative Jay Livingstone | yes |
| Jenn McNary | yes |
| Dr. Ryan Thompson | yes |
| Dr. Dylan Tierney | yes |

**D Tierney** summarized his thoughts on the last full council meeting about NBS. He stated that he thought the meeting went very well; however, we didn’t really have enough time to get to a lot of questions. He thought that the summary and history were very good and really helped educate the council; however, there still seem to be outstanding questions about the process. He asked the committee for their thoughts on the meeting and how they wanted to proceed with the follow-up questions.

**J McNary** stated that she agreed with Dylan’s summary. She thought that we really needed to have a better understanding of how the committee meets and makes decisions. She thinks that the public needs more information about how the council meets. She also thinks that there is an opportunity to give NORD recommendations about their grading criteria for the report card. She thinks that the council needs to explore the NBS program process and see if there is a way that the public can get involved. She believes that the public would be interested if they had more information. One of the reasons she suggested a legislative briefing related to NBS.

**R Thompson** stated that he was not able to attend the entire meeting due to work obligations however he is very interested in the topic and the summary makes a lot of sense. He also agreed that understanding how the Massachusetts process works would be very helpful.

**Rep Livingstone** stated that he appreciated the discussion. He thought that it was a very good meeting but he agreed that there may be more discussion needed. He thought that the NORD discussion was very helpful. As a legislator, he always likes to know how Massachusetts measures up to other states. He thought that the history was very helpful to hear, but we now needed to understand the process and let council members ask questions about the process. He commented that it wasn’t clear how much input the NBS program was open to public input.

**D Tierney** asked how the council can make recommendations on how to improve the MA NBS program. He proposed that we have Dr. McAlmon attend the next full council meeting to talk about the NBS program Advisory Committee and how the program logistics work. Dr. McAlmon is the chair of the NBS Advisory Council. He stated that the NBS program reports to DPH and that Dawn Fukuda will be the person they will now be reporting to. As Dawn stated at the last meeting, she lives with a rare disease and it very interested in the work of the council.

**J McNary** asked if we could elicit questions from the council to give Dr. McAlmon ahead of time. We don’t want her to be on the defensive or feel attacked.

**D Tierney** stated that it would probably be a good idea to give her questions ahead of time.

**J McNary** asked about legislative language for adding disorders to the mandatory screening list. She noticed that Rep McKenna was working on adding language for a specific disorder in the large healthcare bill. She asked the group how that would work.

**Rep Livingstone** stated that he didn’t think that adding disorders through legislative action was probably not the best way. He added that the legislature put the process in place for the current system and it was a very scientific process. He did not think that the legislature would be interested in adding disorders through legislation.

**D Tierney** added that he didn't think DPH would be in favor of that process either. He added that he knows that DPH has approved a form for the public to request the addition of a specific disorder.

**J McNary** stated that it would be important to understand the process by which the committee reviews information and makes decisions. She added that it would be helpful to understand why Massachusetts doesn’t add conditions that have been recommended by federal experts.

**D Tierney** suggested that we ask Dr. McAlmon to attend our meeting in July. If we need to continue the discussion in September, we can.

**J McNary** stated that she would be willing to work on an ad hoc workgroup of members to work through the questions and recommendations.

**D Tierney** stated that it was a good idea and should consider it. He went on to ask what people thought about the topic for our September meeting. Considering our focus areas, he asked if we should start the discussion on telehealth in September.

**Rep Livingstone** added that the healthcare bill will have been finalized by the September meeting, so he would be happy to give everyone an update on what was in the bill at the July meeting. Then, in September, he will be able to give more specifics on what was passed. He can address what was in the bill related to telehealth.

**J McNary** stated that the format of getting experts to talk about an issue was very helpful. She added that it would be really helpful to hear from other agencies about how the bill will affect the rare disease community.

**R Thompson** stated that he would like us to consider medical nutrition. At the meeting with NORD, they gave Massachusetts a score, and it would be great to learn how they scored Massachusetts on this topic and how Massachusetts measures up to other states. He added that medical nutrition is a very important part of the care of patients with rare diseases. His rare disease patients who need medical nutrition are often left searching for a provider that will care for them in the community. He recognizes that access to primary was already difficult, but it’s almost impossible for these patients sometimes. Patients get stuck in the hospital because we can’t find a provider to care for them when they get home. Dr Pasternack has taken many of these patients. In fact, he was mentioned during our meeting about PANDAs. He has taken PANDAs patients. He is an amazing and compassionate provider but is often getting grief about taking these patients because the nurses are unable to find caregivers and medical nutrition support for them in the community.

He would recommend speaking to providers. He knows that providers are maxed out, but it would be helpful to understand the challenges on the provider side. There could be things on the provider side that could help with this difficult situation. He thinks that providers would be willing to brainstorm about finding solutions.

**D Tierney** stated that provider input is very important. He also stated that this problem is complex and may take time to figure out.

**Rep Livingstone** added that it is important to listen to all parties, but we should probably focus on solving bite-sized issues. The complexities of these issues can be overwhelming, and it would be easy to get lost in them. There is the provider side and the patient side, insurance, payers, etc., to consider.

**J McNary** thanked Dr. Thompson for his thoughts about this, as she has experienced the challenges firsthand. Her son had a G-tube inserted at the hospital, and then they couldn’t find anyone to care for it at home. Her son was stuck in the hospital for a month because there were no caregivers in the community willing to care for his medical nutrition at home.

**D Tierney** agreed that the bite-sized approach made a lot of sense. This may allow us to have meaningful discussions while still keeping the big picture in mind.

**R Thompson** agreed with the discussion but would like the committee to consider adding medical nutrition as a topic for this year.

**D Tierney** stated that we could consider working on more than one topic at a time.

He then went on to discuss the annual report and timeline. He stated that there is an internal review at DPH and that we need to complete our work and make our recommendations in time for that review to be completed before it can be submitted. He shared the timeline. No one had questions.

He then asked J McNary to give an update on the Legislative Initiatives and Community Engagement workgroups.

**J McNary** let everyone know that the Community Engagement group was focused on updating the RDAC website. Although the group had only a few members, and she was still trying to recruit new people to help, they were moving along. At this point, they mostly need help with building content.

The Legislative Initiative workgroup has met several times and will meet through the summer to finalize a process for reviewing and tracking legislation that may impact the rare disease community. The legislative session is quiet in the summer so we plan to meet back as a full workgroup in September.

**D Tierney** let all know that it was 11 am and asked for a motion to adjourn.

**Rep Livingstone** made a motion to adjourn, J McNary seconded.

**D Tierney** thanked all for their participation and adjourned the meeting at 11:02 am.