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

**POLICY SUBCOMMITTEE**

REMOTE MEETING: Wednesday April 9, 2025

**Meeting Time 10:00 am – 11:00 pm**

**Meeting Minutes-**Approved July 9, 2025

|  |
| --- |
|  |

**Subcommittee Chair, Glenda Thomas,** welcomed all the meeting. She welcomed new member, Kristen Shannon and let all know that Yue Huang and Tai Pasquini would be stepping away from the policy subcommittee to focus on the research subcommittee. The thanked both of them for their work on the committee.

She let all know that the meeting was open to the public however only members on the agenda were allowed to speak. She asked that anyone on the call who was not on the agenda, should mute their microphone and turn off their camera. She then proceeded to a roll call to establish a quorum and call the meeting to order.

**Roll Call**

|  |  |  |
| --- | --- | --- |
|  | Member | Present |
| 1 | Glenda Thomas | X |
| 2 | Jenn McNary | X |
| 3 | Tai Pasquini | X |
| 4 | Yue Huang | X |
| 5 | Representative Jay Livingstone | X |
| 6 | Representative Joe McKenna | X |
| 7 | Kristen Shannon | X |

**G Thomas** called the meeting to order at 10:03.

She then asked if all received the minutes from the last meeting on January 8th. All agreed. She asked if anyone had any edits or corrections. No one responded. She asked for a motion to accept the minutes as presented. Y Huang made a motion and J McNary seconded. GT then conducted a roll call vote.

|  |  |  |
| --- | --- | --- |
|  | Member | approved |
| 1 | Glenda Thomas | X |
| 2 | Jenn McNary | abstained |
| 3 | Tai Pasquini | X |
| 4 | Yue Huang | X |
| 5 | Representative Jay Livingstone | X |
| 6 | Representative Joe McKenna | X |
| 7 | Kristen Shannon | abstained |

**G Thomas** stated that the first agenda item would be medical nutrition. She asked Rep McKenna if he had any updates to share.

**Rep McKenna** stated that he didn’t really have any additional information to share. He offered to check with legislative colleagues in other states to see if any other states have passed any medical nutrition laws. He offered to reach out to the

National Coalition of State Legislators to see what other states may be working on.

**G Thomas** asked RDAC member Alison Griffin if she had any thoughts on this topic.

**A Griffin** stated that she thought that there needed to be more education on the need for insurance coverage for medical nutrition.

**Rep McKenna** stated that Congressman McGovern stated that Massachusetts was in support of the federal bill and we probably didn’t have much to do right now.

**D Tierney –** asked if the group thought the federal bill would meet the needs of Massachusetts residents or do we need to evaluate what gaps may still exist in Massachusetts.

**Rep McKenna –** stated that he felt that Health Policy Commission (HPC) and Center for Health Information and Analysis(CHIA) may be able to help us figure out where we stand on this issue. He offered to reach out to HPC and CHIA related to this topic and report back to the group.

**Y Huang –** offered to work with HPC to help with this project. She also agreed that looking at this data may be a good starting point.

**D Tierney –** asked what a report would look like. Is it a white paper or a spreadsheet?

**Y Huang –** stated that the reports vary depending on what is needed. Some are narrative and more like a policy brief and some are more typical spreadsheet analysis reviews.

**A Griffin –** offered to offer her experience related to this topic. She stated that generally MassHealth provided good coverage however Medicare was a very poor payer of this type of support. The criteria is very restrictive.

**G Thomas –** offered information about NORD tracking of legislation. She stated that some of the states are working on topics like newborn screening, biomarkers, and pediatric cancer. She then asked if Rep Livingstone to give an update on legislative issues. She also shared a spreadsheet on how they track legislative initiatives.

**Rep Livingstone -** then described the legislative process. He started by stating that last fall, he gave an update on bills of the 193rd session last fall. Bills either became law or are now dead. This is now the beginning of the 194th legislative session. This session started on January 1, 2025. She shared that he started a review using the following topics:

Telehealth, Newborn Screening, Homecare, Nutrition, and Access to out of network providers. He stated that his staff have put hyperlinks on the spreadsheet so that subcommittee members can look into more detail about the bills.

**K Shannon –** asked if there was an interest in a topic not on the list, how would we find out about it.

**Rep Livingstone** stated that he would be happy to look at other topics, members should email him if there was another topic for the spreadsheet. He then explained that there are often many bills related to the same topic. The bills will often hold hearing to consolidate the information. The bills will often take on many versions before moving forward.

**G Thomas** asked how to learn more about the bills.

**Rep Livingstone –** stated that all the bills on the spreadsheet are Massachusetts legislature. There are no federal bills on the list.

Sometimes a sponsor will try to pass a narrow bill then look at expanding it after the restrictive bill passes. Sometimes it’s hard to get a bill passed that is very comprehensive due to the cost implications.

**G Thomas** asked about the best way to proceed as an RDAC.

**Rep Livingstone –** stated that the legislative process can be very convoluted. When he sponsors a bill, he knows that it will have many iterations before moving on. Several people way in on the bill. If it involves money it has to go to Ways and Means. Once a bill passes the House it goes to the Senate. They will go through a similar process. Once a bill goes to the Senate floor, the language usually doesn’t change.

**D Tierney –** asked if it was possible to add Rare Disease language to existing bills when appropriate.

**Rep Livingstone –** sometimes it’s hard to add general language on a rare disease due to the unknown costs associate with it. For example, the bill on medical nutrition specifically related to covering nutrition for Crohn’s Disease. If it passes maybe, looking at expanding it to other rare disease conditions may be possible.

**Y Huang** asked if there was a definition of medical nutrition for our discussion?

**G Thomas –** next steps review

* Rep. McKenna will check into what other states may be doing related to medical nutrition and work with HPC and CHIA related to an analysis on medical nutrition.
* Everyone will get acquainted with the spreadsheet
* Glenda will work with Alison to come up with daft of the definition of medical nutrition for review at our next meeting

She then asked if there was a motion to adjourn

**Rep Livingstone** made a motion to adjourn

**K Shannon** seconded

**G Thomas** adjourned the meeting at 11 am and let all know that the next meeting will be on July 9th from 10-11 am.

|  |
| --- |
|  [https://us06](https://us06web.zoom.us/j/83407469310?pwd=bW1WQlp6MkVCMkhLdGpqU1VaU3FSQT09) |

LET ALL KNOW THAT THE NEXT MEETING IS JULY 9, 2025 FROM 10:00 AM – 11:00 AM

Ask for a motion to adjourn; need a second. Ask if all are in favor.

STATE THE MEETING IS ADJOURNED AT \_\_\_\_\_\_\_\_(time)