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

**Legislative Initiatives Workgroup Meeting Agenda**

Monday, April 22, 2024

**MEETING TIME 11:00 am – 12:00 pm**

Meeting Minutes (approved 5.6.24)

**ZOOM REMOTE MEETING:** <https://zoom.us/j/93538003513?pwd=amtvQXNxVTkrYXFNT2RnM2V1QnNTZz09>

**Jenn McNary and Glenda Thomas,** co-chairs,welcomed all to the first meeting of the Legislative Initiatives workgroup and called the meeting to order at 11:02.

Members present: Jenn McNary, Glenda Thomas, Tai Pasquini, Yu Huang, Representative McKenna and (Cassidy Trablicy) Representative Livingstone.

G Thomas opened the meeting, thanking all for their participation. She asked all to review the document sent prior to the meeting (below) She asked if all agreed with the goals and objectives of the workgroup.

***Goal:*** *To Identify how existing and future legislative initiatives can address issues facing the rare disease community.*

***Objectives***

1. *FY2024 (ending June 30. 2024)* 
   1. *Formulate the Legislative Initiative Subcommittee – finalize goals and objectives for FY2024 and FY2025.*
   2. *Focus areas will follow the full RDAC key initiatives:*
      1. *Telehealth*
      2. *Newborn Screening*
      3. *Medical Nutrition*
      4. *Home care services (access and reimbursement)*
      5. *Access to out-of-network providers*
   3. *Create the criteria “workflow” for determining whether a bill or legislative effort impacts the rare community in our priority areas.*
   4. *Create a way to track legislation in Massachusetts that impacts the rare disease community.*
      1. *Create a Google Doc for internal use by the subcommittee.*
      2. *Develop a list of key works to focus on information search.*
      3. *Identify resources available to assist with legislative research.*
   5. *Draft and email other state RDACS inquiring about their legislative bills/initiatives.*
2. *FY2025 (July 1, 2024 to June 30, 2025)*
   * 1. *Identify what other states are doing related to tracking legislation and determine if there are GAPS for MA to address.*
        + *Create a way to track legislation related to rare diseases in other states.*
        + *Identify resources available to assist with working with other states’ RDACs.*
     2. *Monitor MA legislative bills/efforts and summarize the status of legislative actions and any future actions required.*
     3. *Provide updates/reports at the scheduled full council meetings.*

All reviewed the document and agreed with the goal. After discussion about the objectives, all agreed that identifying and tracking legislation that may impact the rare disease community was a priority for the RDAC; however, they would most likely not be able to advocate for legislation or even contribute to the creation of legislation. As a legislatively appointed council, the council could not act in an advocacy role. However, after discussion, they agreed that they could identify and track legislation as an educational objective. Council members could advocate as individuals, just not as a council.

The group discussed how they would know what legislation was important to the rare community and based on the steering committee priorities for 2024, they decided to prioritize the following topics for legislative review:

* Telehealth
* Newborn Screening
* Medical Nutrition
* Access to out-of-network providers
* Home care services

The group agreed to develop keywords related to these topics and send them to Glenda. These keywords would help in the identification and tracking of legislation.

The group also discussed developing criteria for prioritizing bills and legislation. They felt that having clear criteria for prioritizing would help the group stay focused.

They also agreed that having these topics as a focus for our full council meetings would be very helpful. The May meeting would focus on Newborn Screening, and the July meeting would focus on telehealth. They agreed to add information about legislation related to these topics during the meeting.

The then discussed a meeting schedule for the workgroup and agreed to meet every other week until July 1st. The meetings will be from 11:00 am to 12:00 pm, and Mary Lou will set up the meetings and send out the schedule with invites.

The group also asked if the DPH attorney could attend the next meeting on May 6th to discuss what the RDAC can and cannot do related to legislation. Mary Lou will work with Dylan to arrange for the attorney to attend this meeting.

J McNary made a motion to adjourn, T Pasquini seconded, and G Thomas adjourned the meeting at 11:46.