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

**Legislative Initiatives Workgroup Meeting Agenda**

Monday, May 6, 2024

**MEETING TIME 11:00 am – 12:00 pm**

Meeting Minutes Approved 5.20.24

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

**Jenn McNary and Glenda Thomas,** co-chairs,welcomed all to the meeting at 1:02 pm.

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 if they received the minutes from the last meeting (4.22.24), and if anyone had any revisions or corrections. All received and not revisions. Representative McKenna motioned to accept the minutes as presented. J McNary seconded. Minutes approved.

G Thomas then asked if everyone had reviewed the revised Goals and Objectives (below) and if anyone had any edits. No one had edits. She asked for a vote to approve the Goals and Objectives. There was unanimous approval.

***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 specialty care, including 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 compare to MA*
			+ *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.*

J McNary and T Pasquini gave an update on discussions with NORD. She let all know that other state RDACs have legislative committees. She thinks about 4-5 states have one. She asked if all would like to have the other states report to them about what they are working on. All agreed. T Pasquini will follow up with NORD to see if they can assist with contacting the other states.

G Thomas then asked the legislator on the call if they could give a summary of the legislative process.

Rep. Livingstone began by reviewing the legislative process. He first explained that there were different ways that bills are enacted. There are formal legislative sessions and there are informal legislative sessions. People may not realize that bills can become law through an informal process. Formal legislative meeting occur from January to July of each year. Informal session can occur anytime between July 1 and January. If there is discussion during an informal session however, the bill only needs one objection to end the discussion and then the bill is dead. Bill in formal sessions must follow a specific timeline and process. A bill must be presented in January to meet the criteria for formal session. Late filed bills have an additional procedural step. It is also important to note that it is uncommon for a bill to become law without any edits to the language. Bills often are modified and edited during the process. It is rare for a bill to become law with the same language it was originally presented. Bills may also be combined with other bills and the numbers will change in the process.

Committee chairs can have a lot of influence over bills. If the committee chair likes a bill, it is likely to become law.

J McNary asked the representatives how the RDAC could best support their work and bills that are important to the rare community.

Rep Livingstone added that the RDAC could best support bills that are important to the rare community by providing education and testimonials. He added that it is easier to stop a bill than to get a bill passed. One member can change the direction of a bill. It is very important to talk with the bill's sponsor prior to doing anything. He stated that he likes to talk with anyone he thinks may oppose a bill first. Healthcare bills are very difficult because there are usually many bills related to healthcare that get traction. There has been a healthcare bill passed every term I have been in office, and that is five. He added that he felt that the RDAC’s greatest power is as a resource for information and patient stories.

Rep. McKenna added that he realized that the RDAC could not advocate or lobby for specific bills, but they could provide education and resources to the legislature through learning sessions where patients could share their stories. Many non-profits will come for specific causes and provide information and patient stories for legislators.

Rep. Livingstone added that it was important to note that supporting a bill comes in many forms. If a bill has good support and is on track to pass, it’s sometimes best to do nothing. He recommended that if the council is interested in a specific bill, he or Rep McKenna should call the sponsor to see how best to support it.

G Thomas asked if there were any bills on newborn screening or telehealth up for consideration.

Rep Livingstone stated that it is sometimes hard to know where a bill is in the process. Although it is in the public domain, it’s sometimes hard to follow as the bill's language and number may change. Sometimes, bills get sent to committee to study. Usually, that happens when a bill isn’t getting enough traction to move forward.

J McNary stated that she has been working on the criteria to determine what bills the RDAC should follow, and she hoped to get that back to the group by the next meeting. She also stated that she was working on keywords for searching bills and asked if anyone else could help with that.

Rep McKenna added that keywords sometimes don’t get all the answers. For example, he shared that he filed a bill for testing newborns for lysosomal storage disorders, but he didn’t include the words newborn screening or rare disease in the language. Therefore, keywords for newborn screening or rare disease won’t find it. One thing we may want to think about is ensuring that legislators include rare disease in the language of any bill that impacts the rare disease community. He recommended coming up with keywords but to realize that it may not capture everything.

G Thomas asked all how we could determine the impact of a bill on the rare community.

J McNary summarized by stating that the workgroup would ask the legislators on the committee to speak to the sponsor of any bills of interest before the RDAC does anything.

She stated that if advocacy was needed, she was willing and able to mobilize people on her own time. G Thomas agreed to do the same.

J McNary then asked T Pasqini if she would reach out to NORD and report back at the June 3rd meeting about what other state RDAC legislative committees are doing. She will ask them to come to that meeting if possible.

Rep Livingstone added that the statehouse news was also a good resource for the committee to review a bill's progress. The statehouse news can be very informational.

G Thomas asked if there was any new business. No response. Then asked if there were any announcements. No response. She then asked if there was a motion to adjourn.

T Pasquini made a motion to adjourn. J McNary seconded.

G Thomas adjourned the meeting at 11:50.