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

**Legislative Initiatives Subcommittee Meeting Agenda**

Monday, May 20, 2024

**MEETING TIME 11:00 am – 12:00 pm**

Meeting Minutes Approved 6.3.24

**ZOOM REMOTE MEETING:**

<https://zoom.us/j/92713945954?pwd=VGwrcmw2V1lqdlo3NGd5WlBBWU1yZz09>

**Welcome** by Jenn McNary, committee co-chair. She called the meeting to order at 11:02 am

**Participants** present Jenn McNary (co-chair), Representative Jay Livingstone, Cassidy Trabilcy (Rep. Livingstone staff), Representative Joe McKenna, Tai Pasquini, Yue Huang, Dylan Tierney (RDAC Chair).

 **J McNary** asked if everyone had received the minutes from the last meeting and if anyone had any revisions or edits. She also requested a change to the wording of V under “focus areas.” She requested a change from “access to out-of-network providers” to “access to specialty care, including out-of-network providers.” She asked if anyone had an issue with this. All agreed with the change. She then asked for a motion to accept the minutes as modified.

T Pasquini made a motion to accept the minutes as modified. Y Huang seconded the motion.

The minutes were unanimously approved as modified.

**J McNary** then presented a list of keywords that could be used to identify legislation related to the rare community. (List below) Items in red were modified during the meeting.

**Y Huang** requested to add specialty care as well as out-of-network care

**T Pasquini** requested to add orphan drugs

**Y Huang** requested to add Personal Care Management

**T Pasquini** requested to add gene therapy and MassHealth Connector marketplace

**J McNary** requested to add Health Saving Accounts

**J McNary** then asked if there were any other suggestions or recommendations for the list.

No additions were requested.

**Relevant Subjects for tracking**

Newborn screening

Diagnostics /testing

Diagnosis

Access

Coverage

The Mass Health Connector Marketplace

Health Savings Account

Home Health

Personal care attendant (PCA) program

Personal Care Management

Complex Care Management

Home health nursing

Rare disease

Physical therapy

Special Education (IEP/504)

Telehealth

MassHealth

Medical Nutrition

Durable Medical Equipment

Housing for disabled individuals

Supplemental income

Mass Rehab

Specialty care

Out of Network Care

Orphan Drugs

Gene Therapy

Medicaid

Drug utilization, Pharmacy and Therapeutics (DUR,P&T)

Transportation (the Ride, Medical Transport, Public transportation )

Mental Health

Caregivers Issues

**J McNary** then asked if all could look at the criteria she drafted for engaging related to the legislative effort. (Criteria are presented below) She asked for comments and discussion.

**Criteria for engaging/learning more about legislative efforts**

1. Must **impact** rare stakeholders in MA
2. Be **supported/Opposed** by one or more rare stakeholders (including patients, caregivers, advocacy organizations, industry, institutions/hospital, service providers ).
3. Currently **Active**

**Rep McKenna** added that the word “active” was very good to include. He stated that it would be important to focus on active legislation in order to be most efficient. It will also help prioritize our efforts.

**J McNary** summarized the discussion by stating the next steps:

1. Define search terms
2. Bring bills to the workgroup
3. Workgroup to determine which bills to pursue based on established criteria
4. Bring results to full council for discussion

**Rep Livingstone** added that is would be important to remember that the council’s role is to educate and not advocate.

**Rep McKenna** gave an update on the current healthcare bill. He stated that this bill has already left the house so there really isn’t much to do at this point. It is in the Senate now and most likely there will be modifications, revisions and even possible additions. It will not look the same as it did when it left the House. It may go to conference committee and the plan is that is will most likely go to the governor’s office by July 31st. There is usually only one healthcare bill per year so it’s important to be involved through the process.

**Rep Livingstone** added that Representative Kane added some language related to rare disease before it left the House.

**J McNary** thanked the representative for their discussion. She then asked if there was any other comments or topics for discussion.

**T Pasquini** stated that she is in communication with NORD. They are willing to communicate with other state RDACs about what they are doing related to legislative initiatives. She will follow up with NORD and report back to the committee if she has more information.

**Rep. Livingstone** provided an update on the current healthcare bill. He added that any work that the council could do related to healthcare would most likely need to be done next term as this year's bill is already in process. He recommended that the council stay educated on the changes that may occur with the bill in the Senate. The Senate version may be very different. As a council, we should think about issues for the next legislative term.

**J McNary** thanked all for their thoughtful discussion and asked if there was a motion to adjourn.

**Rep McKenna** made a motion to adjourn. **T Pasquini** seconded.

**J McNary** adjourned the meeting at 11: 32