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

**Legislative Initiatives Subcommittee Meeting Agenda**

Monday, June 3, 2024

**MEETING TIME 11:00 am – 12:00 pm**

Meeting Minutes (approved 7.15.24)

**ZOOM REMOTE MEETING:**

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

**Welcome** by Glenda Thomas, 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), Yue Huang, Dylan Tierney (RDAC Chair), Thera Meehan (Guest)

**G Thomas** asked if everyone had received the minutes from the last meeting and if anyone had any revisions or edits. All agreed and no one had any edits. She asked for a motion to accept the minutes as presented. J.McNary motioned to approve, Y Huang seconded. Minutes unanimously approved.

**J McNary** then asked if Rep Livingstone had any legislative updates for the group.

**Rep Livingstone** stated that the House has passed a large healthcare bill and it was now in the Senate. He added that the House also passed a nursing home bill that has been in the Senate for a while. The House is planning to discuss a maternal health bill soon.

**J McNary** asked if there was anything in the bills that may impact the rare disease community.

**Rep Livingstone** stated that he was sure about the nursing home bill, but the maternal health bill included something about newborn screening proposed by Rep McKenna, but he didn’t think it made it through revisions. He added that Rep Kane added some language in the healthcare bill to include rare disease and there may be something related to insurance that could impact the rare community. He plans to thoroughly review the bill and present a summary at the next full council meeting in July. He should have a good idea of where things are at that point as the formal session ends on July 31st.

**G Thomas** asked if there was anything that the RDAC should be doing related to these bills

**Rep Livingstone** added that sometimes there are summary documents but not all bill will have one. He expects the healthcare bill to have a summary document and added that most large bills will have one.

**G Thomas** stated that she wanted the council to be able to let the rare community know about any bills that may affect them.

**J McNary** added that she would like to know when there may be an opportunity to add language about newborn screening for rare diseases. Maybe for Massachusetts to be RUSP-aligned (https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp).

**Rep Livingstone** stated that he would review the maternal health bill and report back. He added the bill # for the chat (malegislature.gov/Bills/193/H4487)

**D Tierney** stated that DPH may not support adding newborn screening for specific diseases to the legislative language. He stated that during the last full council meeting, we realized that maybe the newborn screening process may be improved but adding tests through legislation may not be the best route. He added that he had asked the chair of the Newborn Screening Advisory Committee to attend the next full council meeting to let everyone know how the current process is conducted.

**J McNary** added that we could look at the process of the NBS program. It could be more transparent. She also expressed that adding tests will help people with a diagnosis. We know people often go through a diagnosis odessey and maybe NBS can help narrow down the testing to get to a diagnosis.

**D Tierney** asked all to be cautious when putting NBS and diagnosis into the same context. He felt that we needed to keep NBS and diagnostics separate.

**J McNary** stated that she has heard from the community that NBS can expedite diagnosis.

**G Thomas** added that she agreed that we should also realize that sometimes adult onset rare disease could have been diagnosed at birth.

**J McNary** stated that although NBS doesn’t cover all rare diseases and we need to treat NBS and diagnostics separately but, if adding tests can help people get to a diagnosis faster, we should consider it.

**G Thomas** invited guest speaker Thera Meehan to speak about how she can help with legislative tracking.

**T Meehan** introduced herself as the policy and regulatory person for the Bureau of Infectious Disease as the Department of Public Health (DPH). She stated that almost all DPH programs have a person who tracks legislation to monitor if any legislation may impact their programs. Her role is to track and monitor and then let the appropriate people know if there is something of concern. I have reviewed your search words and could use this list to identify and track legislation.

**J McNary** added that the group also put together criteria that we will use to track and follow legislation. The keywords and criteria are below.

**Relevant keywords for tracking legislation**

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

**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/hospitals, and service providers).
3. Currently **Active**

**T Meehan** added that legislation often flushes out over time. Once we have a list of legislation, we can follow it. It often changes through the process. Names and numbers may change, and most often, the language will change.

**J McNary** asked how she tracks legislation. Is it the same software that is used by Representative Livingstone’s office? We want to make sure we don’t duplicate efforts. We know all of your time is valuable and we want to figure out a process that utilizes both of your expertise and doesn’t duplicate your work.

**T Meehan** stated that DPH uses Instatrack.

**Rep Livingstone** stated that they do not use InstaTrack. He added that it is proprietary software and is not used by the legislature. He added that they use a different tracking software. Once his office recognizes a bill they want to track, they look for updates along the process. He suggested that his office could track bills once the workgroup identified them. Sometimes, there is discussion within the legislature that may help to understand what is happening with the bill.

**J McNary** asked if Rep Livingstone could share any bill summaries that come out. She noted that some bills are just so long and hard to read, it’s hard to know what it all means.

**Rep Livingstone** added that there are not always summaries but when a bill is large or complicated there is often a summary documents and he would be happy to share that.

**G Thomas** asked what people thought the workgroup should focus on right now as it sounds like the next time we will have bills to look at is next January. She asked Thera if she could share a sample of the type of spreadsheet she uses to track legislation.

**T Meehan** stated that she could definitely share a sample spreadsheet of what she tracks.

**J McNary** thanked Thera for her help. She added that she continues to learn and knows that this process will help the whole group to understand legislation and its process better.

She asked everyone if it made sense to meet monthly over the next six months and focus on refining the process for tracking legislation. She suggested that Thera create a list of legislation based on the group’s keywords. After that, Rep. Livingstone’s office could review the list and give us any insights on the bill and how it may impact the rare disease community.

**Rep Livingstone** added that we need to remember that a bill that starts in January may look very different at the end. He stated that his office would be happy to help.

**J McNary** summarized the discussion by stating that it probably doesn’t make sense for us to focus on any specific legislation right now as it is too late in the process. She asked the group if it made sense to reconvene in September.

**Rep Livingstone** added that he felt September was a good time for the next meeting. He will be very busy in the summary preparing for his primary. The summer is usually very slow at the state house.

**G Thomas** asked if we could meet monthly to refine the process.

**Y Huang** suggested revisiting our keywords and narrowing down our focus. She added that HPC has been reviewing legislation on insurance coverage and billing. She recommended a short list based on the council’s priorities for 2024 and 2025.

**J McNary** added that we should also consider our review based on the public comments. Once we know the topics and issues in the legislation, we can report back to the rare disease community. This will be awareness about the bill. Our job is to educate and increase awareness. One we meet with the attorney we will have a better idea of what else we can do but at least now we know that we can educate.

**J McNary** asked for a motion to adjourn.

**G Thomas** made a motion to adjourn. Rep Livingstone seconded.

**J McNary** adjourned the meeting at 12:02