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

**Steering Committee Meeting Agenda**

Thursday, April 11th, 2024

**10:30 am – 11:30 am**

**MEETING MINUTES Approved 6.20.24**

**ZOOM REMOTE MEETING:** https://us06web.zoom.us/j/87657398212?pwd=bVCBohKGxJZSinUzz2rxJbrLxMPdIY.1

**Welcome:** Dr. Dylan Tierney welcomed all to the meeting. He discussed the steering committee membership flux over this year. He thanked Rep. Hannah Kane for her leadership on the council and specifically on the steering committee over the last term. He thanked Rep Jay Livingstone for joining the steering committee as Rep. Kane’s term expired. He also thanked Dr. David Miller and Guadalupe Hays-Mota for their time on the steering committee.

Dr. Tierney recognized the members present: Jenn McNary, Dr. Ryan Thompson, Rep Jay Livingstone and himself. Cassidy Trabilcy also present.

Dr. Tierney held a roll call vote for approval of the minutes from the last meeting on December 19, 2023. He asked if all received the minutes. All replied yes. He asked if there were any edits or revisions, and all responded no.

Dr. Thompson made a motion to accept the minutes as presented, J McNary seconded the motion. Minutes were unanimously accepted with the exception of Rep. Livingstone, who abstained as he was not present at the December meeting.

Dr. Tierney asked J McNary to give everyone an update on the community engagement workgroup. J McNary let all know that the workgroup had met once. The group solicited help from several industry partners and received a draft marketing plan for their review. The workgroup is currently reviewing the plan that focuses on increasing awareness of the RDAC, along with recommendations to update the website. She stated that the group was planning to meet soon to discuss next steps.

Dr. Tierney asked what the overall strategy of the marketing plan was.

J McNary stated that it was two-fold. Primarily, it was to increase awareness of the RDAC, and secondly, it was to collect data from the rare disease community to understand the needs of the rare community. She stated that they created a survey tool; however, it has not had a good response rate. She stated that getting people engaged and willing to put in the time to accomplish the goals has been hard. The current workgroup consists of Rep. Jay Livingstone, Glenda Thomas, Shivang Patel, and herself. She welcomed any additional help.

Dr. Tierney asked all of us how we engage other members.

J McNary stated that she hoped that new members may bring new blood to the council.

Dr. Tierney stated that approximately one-third of the members would be turning over this year. He let everyone know that we have submitted recommendations for new members, and the process is out of our hands. He is hopeful that new members will be appointed sometime in the next few months.

J McNary added that we tried volunteering members to specific tasks; however, this has not been an effective strategy. We are hoping that the new members will be engaged and willing to put in the time to get the work done.

J McNary updated the committee on the Legislative Initiative workgroup. She added that this was a new workgroup that had not met yet. The first meeting will be next week.

Dr Thompson thanked Jenn for all her hard work on the council. He added that one of the challenges of this council was that we are supposed to be advisory in nature. Our goals are to provide recommendations to the governor, the legislature, and the Department of Public Health. He thinks that a lot of the work of this council was executive function type work and maybe we need to be more specific about the expectations of the members, especially as we bring on new members.

J McNary stated that she welcomed any help.

J McNary stated that the Legislative Initiatives workgroup hoped to identify legislation impacting the rare community. She hopes that the group can track legislation and update everything as things progress. She also hopes to look at other states to see what legislation has had a positive impact on the rare community. One of our primary tasks is to develop criteria for reviewing and identifying legislation.

Dr. Tierney thanked Jenn for all her hard work.

J McNary asked about the council's role in legislation. She asked if the council could weigh in on legislation as she was not clear on what the group could or could not do.

Rep Livingstone stated that he did not believe the group could weigh in on legislation. As a legislative council member chaired by DPH, he did not believe we could speak for or against specific legislation.

J McNary added that it would be very helpful to have clarity on what the council could and could not do as far as legislation.

Rep Livingstone felt that the council should focus on identifying the problems of the rare disease community and possible solutions. He added that there were legislators on the council for a reason. If the council can identify the problems and possible solutions and put them in the annual report, legislators could use it to advocate for legislation that would resolve the identified problem.

J McNary stated that identifying problems that could be resolved with legislation could be a goal of this workgroup.

Rep Livingstone added that the legislative language of the council states that it is an educational and advisory body.

Dr. Thompson reinforced that the RDAC’s role was to be an advisory council. He added that if we can focus on identifying the problems and possible solutions, the governor and legislature could use this information to help find solutions.

J McNary added that the steering committee's first charge might have be to identify the priority problems. Over the past three years, we have heard from members of the rare community.

Dr Tierney stated that the NORD report card, discussed at our last full council meeting, identifies three areas for improvement for Massachusetts.

* Medical Nutrition
* Telehealth
* Newborn Screening

J McNary added that over the course of the past three years, we have heard that access to out of network providers as a problem and coverage and access to home care was another.

Dr. Tierney stated that maybe it would be helpful to strategize about our meeting agendas. Maybe we should have a speaker on one of the identified topics at each of our full council meetings.

Rep Livingstone added that the NORD areas would be important to look at. He stated that telehealth is very complicated and confirmed that getting a speaker on Telehealth would be helpful. He added that although telehealth was complex, we should look at it through the lens of the rare community.

J McNary added that this was also true of the home care issues. It is a very complex issue and the rare disease community is very dependent on it. We should do the same for home care: review the issues that are specific to the rare community.

Dr Tierney asked if the legislative workgroup could look into legislation related to the five areas identified.

Rep Livingstone added that some states are looking into the drug approval process. This creates challenges for people with a rare disease, and I wondered if that should be another topic we look at. He recommended that we maybe look at what other states are doing in this area.

Dr. Tierney then shared the timeline for the annual report. He stated that the review process takes time, and we want to stay ahead of the timeline this year. It will be important to submit this report on time so that the legislature can use it to create or support legislation that is important to the rare community.

Dr Tierney asked for a motion to adjourn.

J McNary motioned to adjourn.

Dr Thompson seconded

Dr Tierney adjourned the meeting at 11:29