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

REMOTE MEETING:    Thursday, December 9, 2021, 9:00-11:00 AM

<https://statema.webex.com/statema/onstage/g.php?MTID=ec2a33dac19e7604a9b9c89e5b857e70e>

* Welcome

Dr. Tierney welcomed members to the second meeting of the RDAC and review the agenda items.

* Roll Call

Roll call was taken by Dr. Tierney

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| **Council Member** | **Present** |
| Charlotte M. Boney, M.D | x |
| Janis Creedon |  |
| Ms. Lisa Deck | x |
| Andrew A. Dwyer, PhD, FNP-BC, FNAP, FAAN | x |
| Michael R. Green, M.D., Ph.D. | x |
| Julie D. Gortze | x |
| Guadalupe Hayes-Mota | x |
| Representative Hannah Kane | Anna Darrow represented Rep Kane |
| Andrew A. Lane, MD, PhD | x |
| Representative Jay Livingstone | x |
| Jeff R. Livingstone, PhD | x |
| Diane Lucente, MS, LCGC |  |
| Alexsandra B. Mahady | x |
| Jenn McNary | x |
| David T. Miller, MD, PhD | x |
| Tai Pasquini, PhD, MPA | x |
| Shivang Patel, Pharm.D. | x |
| Asma Rashid, MS, CGC | x |
| Michele Rhee, MBA, MPH | x |
| Robert E. Schultz | x |
| Celia Segel | x |
| Michael Sherman, MD | x |
| Senator Bruce Tarr |  |
| Ms. Glenda E. Thomas | x |
| Ryan Thompson, MD, MPH | x |
| Dylan Tierney, MD, MPH | x |
| Ann Wessel, MS, RD, LDN | x |
| Ross Zafonte, DO | Prior to meeting indicated unable to attend |

Members not present at the 9/16/21 meeting were asked to introduce themselves:

Dr. Michael Green had audio difficulties.

Dr. Shivang Patel, Director of Pharmacy Operations, Metrowest Pharmacy. Interest is on access to resources for patients; would like to see all resources on one platform.

Dr. Michael Sherman, Chief Medical Office, Point32 Health. Interest in treatment and coverage. Drug affordability and coverage is a problem in the rare disease community as many patients have no other choice but to pay costly prices. How can MA balance access and affordability? Looking at biomarkers vs. symptoms would be more beneficial for patients.

* Approval of 9/16/21 meeting minutes

Dr. Jeff Livingstone requested two edits on page 5 of the meeting notes.

All members present (exception below) accepted and approved the minutes.

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| **Council Member** | **9/16/21 meeting minutes approval** |
| Charlotte M. Boney, M.D | x |
| Janis Creedon |  |
| Ms. Lisa Deck | x |
| Andrew A. Dwyer, PhD, FNP-BC, FNAP, FAAN | x |
| Michael R. Green, M.D., Ph.D. | Could not vote due to poor internet connection |
| Julie D. Gortze | x |
| Guadalupe Hayes-Mota | x |
| Representative Hannah Kane |  |
| Andrew A. Lane, MD, PhD | x |
| Representative Jay Livingstone | x |
| Jeff R. Livingstone, PhD | x |
| Diane Lucente, MS, LCGC |  |
| Alexsandra B. Mahady | x |
| Jenn McNary | x |
| David T. Miller, MD, PhD | x |
| Tai Pasquini, PhD, MPA | x |
| Shivang Patel, Pharm.D. | x |
| Asma Rashid, MS, CGC | x |
| Michele Rhee, MBA, MPH | x |
| Robert E. Schultz | x |
| Celia Segel | x |
| Michael Sherman, MD | x |
| Senator Bruce Tarr |  |
| Ms. Glenda E. Thomas | x |
| Ryan Thompson, MD, MPH | x |
| Dylan Tierney, MD, MPH | x |
| Ann Wessel, MS, RD, LDN | x |
| Ross Zafonte, DO |  |

* Presentation from NORD (National Organization for Rare Disorders)

Annissa Reed, MPH, State Policy Manager, Eastern Region

Dr. Tierney introduced Annissa Reed from NORD.

Ms. Reed presented slides (see separate attachment).

Dr. Tierney explained that NORD has helped MA connect to other RDACs across the country; MA can learn a lot from NORD.

Ms. Michele Rhee asked if other RDACs have conducted surveys and if NORD could help with data collection. Ms. Reed indicated other RDACs have conducted surveys or needs assessments in their states. NORD does not collect data. The baseline data from surveys or needs assessments can be very helpful. Some states have posted their surveys online. Ms. Deck requested NORD send out the survey links. Ms. McNary asked how states have disseminated their surveys. Ms. Reed indicated states has used a variety of methods: personal networks, patient/caregiver groups, posting on websites, using existing email lists/listservs. NORD can help get the word out about state surveys through social media.

Dr. Sherman commended NORD; has attended NORD meetings; impact of NORD is making “rare disease” not “rare.” Ms. Reed responded that NORD is able to address 7,000 different rare diseases because the issues associated with all diseases are similar. NORD looks forward to seeing what the MA RDAC will do.

Dr. Pasquini asked if NORD is aware of any surveys have been targeted to medical professionals. Ms. Reed thought maybe the state of PA has or is looking into it and she will follow-up.

Dr. Tierney thanks Ms. Reed and looks forward to collaborating with NORD.

* Discussion: Meeting procedures

Dr. Tierney shared the slide below:



And asked the Council to discuss developing or identifying meeting procedures. How does the RDAC decide which issues to address? How does the RDAC formalize the process? Dr. Tierney indicated as chair his job is to facilitate, but he is not a content expert – the members of the RDAC are the experts and need to drive the process.

In addition to developing resources for the care of people with rare diseases, the mission of the RDAC should include supporting quality access to treatment and services and establishing a “clearinghouse” of available services in MA. How does the RDAC identify best practices and remove obstacle to diagnosis and treatment? How does the RDAC reach out to the public?

Dr. Tierney suggested a mission statement be developed to guide the RDAC as well as operating procedures document. The voting process the RDAC must follow is formal but ensures everyone has a voice.

Dr. Tierney asked how the Council would like to use time within a meeting to deliberate? The Council is subject of the Open Meeting Law (OML). The OML discourages communication outside of Council meetings. Perhaps a standing agenda item? Ms. McNary suggested submitting topics for consideration at the end of one meeting, to be discussed at the next.

* Discussion: Working groups/Subcommittees

Dr. Tierney shared the slide below:



Dr. Tierney asked the group to discuss the possible development of a subcommittee/executive subcommittee to determine topics/areas of focus for the entire Council as well the possible development of adhoc working groups. Smaller groups may be able to be more nimble. Any subcommittee/working groups are subject the OML and would need to have a quorum to meet. Suggested a five-person executive subcommittee to be comprised of the Chair, patient/caregiver, legislator, hospital administrator and a researcher/clinician.

Dr. Miller thought the idea of smaller groups/subcommittees make sense as it will be hard to get such as large group to make decisions. One of the smaller groups may focus on the legislature. Ms. Deck stated the Council need to brainstorm together and does not support establishing any sort of gate keepers for the Council. Dr. Tierney responded there are different ways to approach using an advisory council: having the advisory council prioritize issues and present priorities to the group. Dr. Tierney reminded the council they are the experts.

Ms. McNary suggested an executive subcommittee consist of seven members, not just five. Patients and caregivers should be two separate distinctions (parent/caregiver and a person living with a rare disease). Ms. Segel suggested having a member of this subcommittee be involved in administration or finance. Dr. Pasquini indicated some topics would be better suited to adhoc working groups, than the subcommittee. Dr. Miller suggested having someone involved in reimbursement or a payor be on the subcommittee, not sure if this would be covered by the hospital administrator.

Dr. Tierney said the Council would have to vote on the establishment of a subcommittee. Ms. Thomas suggested clarifying the mission of the subcommittee and identifying who will be on it by names, not necessarily roles. Dr. Thompson discussed the process being tricky as too much information/items could be discussed outside of the larger council. A subcommittee should be a sounding board and not have too much authority. Dr. Tierney commented that was a good reflection. Ms. Thomas suggested having two subcommittees, one to identify topics for the Council and one to work on operating procedures. Dr. Tierney replied everyone will be working on/have a chance to review any operating procedures, and he has a copy of operating procedures from another state (MN).

Ms. McNary though an executive subcommittee could determine the focus on any adhoc working groups, as those working groups are where the real work will be completed. Ms. Mahady indicated she has served on other groups that used similar formats and wondered if the RDAC could meet more often, perhaps once a month for 30 minutes? Meeting quarterly is tough. Dr. Tierney responded the RDAC can meet as frequently as they decide they would want to, but the meeting and the agenda need to be publicized at least 48 hours before.

Ms. Rhee asked about a place where documents could be reviewed such as digital boards, or Google docs, allowing only members to be editors of documents? Can the RDAC share documents for review via email? Dr. Tierney shared he will be meeting with the Bureau’s general counsel to discuss this as well as virtual voting vs. in person voting.

Dr. Tierney suggested having an executive subcommittee with seven members instead of five members, based on the discussion. The seven members would be: the RDAC chair, a person living with a rare disease, a caregiver or parent, a legislator, a hospital administrator with finance experience/background, a clinician, and a researcher. Dr. Tierney asked the group to vote. All members present voted yes (exception below):

| **Council Member** | **Would like to establish a subcommittee** |
| --- | --- |
| Charlotte M. Boney, M.D | x |
| Janis Creedon |  |
| Ms. Lisa Deck | x |
| Andrew A. Dwyer, PhD, FNP-BC, FNAP, FAAN | x |
| Michael R. Green, M.D., Ph.D. | Could not vote due to poor internet connection |
| Julie D. Gortze | x |
| Guadalupe Hayes-Mota | x |
| Representative Hannah Kane |  |
| Andrew A. Lane, MD, PhD | x |
| Representative Jay Livingstone | Left the meeting |
| Jeff R. Livingstone, PhD | x |
| Diane Lucente, MS, LCGC |  |
| Alexsandra B. Mahady | x |
| Jenn McNary | x |
| David T. Miller, MD, PhD | x |
| Tai Pasquini, PhD, MPA | x |
| Shivang Patel, Pharm.D. | x |
| Asma Rashid, MS, CGC | x |
| Michele Rhee, MBA, MPH | x |
| Robert E. Schultz | x |
| Celia Segel | x |
| Michael Sherman, MD | x |
| Senator Bruce Tarr |  |
| Ms. Glenda E. Thomas | x |
| Ryan Thompson, MD, MPH | x |
| Dylan Tierney, MD, MPH | x |
| Ann Wessel, MS, RD, LDN | x |
| Ross Zafonte, DO |  |

Ms. McNary asked about folks unable to attend this meeting? Ms. Deck and Ms. Gortze agreed. Dr. Tierney responded the discussion will be written into the minutes.

Dr. Miller suggested nominating members by role/identifying members who are interested by role (nominate or self-nominate). The list below was developed:

Person living with a rare disease – Michele Rhee

Caregiver or parent - Jenn McNary

Legislator – Representative Hannah Kane

Hospital administrator – Dr. Thompson

Clinician – Dr. Miller

Researcher – Dr. Livingstone

Dr. Tierney reiterated the need to discuss further with the Bureau’s general counsel.

* RDAC email list

Dr. Tierney reminded the Council to send only relevant emails to the group. Ms. Mahady requested a list of members and their affiliations be sent to Council members. There was a question about establishing an alternate space or other electronic forum for members to share information/announcements. Ms. Gortze suggested establishing a calendar for members and asked if this could go on the RDAC website. Ms. McNary liked the idea of a calendar that includes MA specific events as well as industry events. Dr. Tierney will explore adding a calendar to the webpage with the DPH web staff, but voiced concern about keeping it updated.

Ms. McNary suggested adding resources/materials to the MA RDAC website and making it more dynamic; other states have nicer web sites. Dr. Livingstone asked is social media (for example Facebook) could be used for the RDAC in addition to the website? It would be easier for RDAC members to post. Other RDAC’s has Facebook pages. Ms. Mahady indicates she participates in a Facebook group for a different DPH group.

Ms. Rhee asked about a site/place to store documents? Should this be the website? Could there be a Dropbox established for the RDAC? A Microsoft Teams folder or a shared google drive? Dr. Tierney will find out more and let the Council know.

* Speaker(s) for future meetings

Dr. Tierney asked the Council if there is interest in having a speaker who is a person living with a rare disease speak at each quarterly meeting. Ms. McNary suggested following the Awareness Calendar and identifying speakers based on the calendar. Ms. Thomas suggested having a person living with a rare disease or a caregiver speak at each meeting. The state of New Hampshire has a model of a person living with a rare disease or a caregiver start off each meeting. Ms. McNary indicated a speaker should be able to speak to the experience in MA. Dr. Pasquini suggested having speakers that prioritize different points of the life cycle of the rare disease journey (such as accessing school for the first time).

* Member Announcements

Dr. Tierney reminded all members of the Conflict-of-Interest Training and the Open Meeting Law materials review and signature page, and asked all make an effort to complete them. Contact Emile Day directly with questions.

There were no other announcements.

Meeting adjourned. Several members thanked Dr. Tierney.

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