



RARE DISEASE ADVISORY COUNCIL

Approved by Vote September 15, 2022

Massachusetts Rare Disease Advisory Council (MA RDAC)
Standard Operating Procedures (SOP)
August 2022

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Council Mission

The purpose of this Advisory Council is to provide guidance and recommendations on rare disease incidence, the status, and the needs of the rare disease community to the governor, the legislature, and the department of public health with the goal of improving the lives of people impacted by a rare disease in the Commonwealth.

Purpose

To establish general procedures for the Council meetings and administrative matters.

Membership

Membership shall consist of 29 voting members, which shall consist of;

- the commissioner, or a designee, who shall serve as chair
- the executive director, or a designee, of the health policy commission
- 2 members of the senate or a designee
 - 1 of whom shall be appointed by the minority leader of the senate
- 2 members of the house of representatives or a designee
 - 1 of whom shall be appointed by the minority leader of the house
- 4 persons appointed by the senate president
 - 1 of whom shall be a pharmacist with experience with drugs used to treat rare diseases
 - 1 of whom shall be a geneticist licensed and practicing in the commonwealth
 - 1 of whom shall be a registered nurse or advanced practice registered nurse licensed and practicing in the commonwealth with experience treating rare diseases
- 4 persons appointed by the speaker of the house
 - 1 of whom shall be a representative of a health plan or accountable care organization certified by the health policy commission
 - 1 of whom shall be a genetic counselor with experience providing services to persons diagnosed with a rare disease
 - 1 of whom shall be a representative from a rehabilitation facility that provides rare disease care
- 15 persons to be appointed by the governor
 - 2 of whom shall be from academic research institutions that receive grant funding for rare diseases research
 - 2 of whom shall be physicians licensed and practicing in the commonwealth with experience researching, diagnosing, or treating rare diseases
 - 1 of whom shall be a hospital administrator, or a designee, from a hospital in the commonwealth that provides care to persons diagnosed with a rare disease

- 1 of whom shall be a hospital administrator, or a designee, from a hospital in the commonwealth that provides care to persons diagnosed with a rare disease and in which the scope of service focuses on rare diseases of pediatric patients
- 3 of whom shall be representatives of rare disease patient organizations that operate in the commonwealth
- 2 of whom shall be representatives of the biotechnology and scientific community who are engaged in rare disease research, including, but not limited to, a medical researcher with experience conducting research on rare diseases
- 1 of whom shall be a dietician licensed and practicing in the commonwealth with experience administering dietary therapies to those with rare diseases
- 2 of whom shall be persons age 18 or older who have a rare disease
- 1 of whom shall be a caregiver of a person with a rare disease

Membership Term

Each member of the rare disease advisory council shall serve for a term of 3 years and shall serve until their successors have been appointed. Members may be reappointed to serve consecutive terms indefinitely.

All members shall be appointed/reappointed as directed by legislation.

Replacement of a Council Member

Upon receipt of a letter of resignation or completion of the three-year term, the council chair shall reach out to the appointing authority, as stated in the legislative language, for the reappointment of an existing council member or the appointment of a replacement council member. The existing council member shall continue to serve on the council until a replacement is appointed.

Membership Compensation

The members of the advisory council shall serve without compensation.

Meetings

Number of Meetings

The advisory council shall meet periodically not fewer than four times annually, with members able to participate in any meeting by teleconference.

Agendas

Meeting agendas will be developed by the Council Chair based on legislative charges and council discussions. According to Open Meeting Law requirements, agendas will be posted on the webpage: <https://www.mass.gov/orgs/rare-disease-advisory-council>. Agendas will also be sent to all members in advance of the meeting.

Public

All meetings will be open to the public.

Meeting Materials

Meeting materials will be posted on the webpage:

<https://www.mass.gov/orgs/rare-disease-advisory-council> Meeting materials will be sent to all members before the meeting.

Role of the Council Chair

The council chair will ensure the goals and duties of the council are carried out as planned and will facilitate meetings to discuss and plan the council's activities.

Role of the Council Coordinator

The council coordinator's primary responsibility includes supporting the chair in facilitating and coordinating all council meetings.

Specifically:

1. Develop and maintain agendas, minutes, and meeting materials in collaboration with the council chair
2. Develop and maintain operating procedures in collaboration with the council chair
3. Organize and maintain all documents as required by Open Meeting Law
4. Email Department of Public Health Web Liaison, Secretary of State, and Accounting and Finance representative to meet the Open Meeting Law Requirements
5. Maintain a member contact list
6. Maintain meeting schedule for council
7. Contact and schedule speakers as directed by the council chair
8. Maintain speaker bureau list
9. Collaborate with other rare disease organizations as directed by the chair
10. Attend all meetings and draft minutes for council review
11. Maintain approved minutes
12. Draft and coordinate review of any council reports

Roles of Members

The member's primary duty is to carry out the intent of the legislative charges. This duty includes actively contributing to efforts to achieve deliverables prioritized by the council about the council's mission. These contributions include participation in Council subcommittees by providing services and expertise towards subcommittee goals.

Voting Procedures

Robert's Rules of Order will be enforced.

Motions: The motion maker must clearly and concisely state and explain the motion. After discussion, the motion shall be restated clearly and concisely by the council chair before a vote is taken. The motion must be recorded in written form, as voted on, and must be part of the record or minutes of the meeting, including the exact vote of each council member.

In the case of a virtual meeting environment, the council chair shall conduct a roll call vote for all votes taken by the council.

A voting member of the council may not vote on any council matter that would have a conflict of interest. The affected member who may not vote may still participate in deliberations relating to the decision after letting the council know of their voting recusal and stating the reason for the recusal.

Meeting Procedures

Facilitation of Meetings

The council chair shall be the facilitator of all full council meetings.

Quorum

Fifteen members of the council members must be present for a quorum. The chair is counted in determining whether a quorum is present. Each council member is asked to notify the council coordinator or council chair at least 24 hrs. before the meeting time if they will not be present.

Member Participation

The council chair may call upon members from time to time to provide background or expertise related to the topic to be discussed.

1. Members should strive to attend all meetings and arrive on time. A member who cannot participate in a meeting should notify the council coordinator in advance of the meeting to ensure quorum can be met. Members can send a person to represent their views when they cannot attend. The member representative will not have voting rights unless sworn explicitly in as a representative member of the council.
2. Members should come to meetings prepared for discussion by reviewing any information sent by the council chair and/or coordinator and be prepared to participate.
3. Members shall recognize the legitimacy of concerns and interests of others, whether or not they agree with them. Members shall participate in the spirit of collaboration and consensus.
4. Members shall share discussion time and encourage everyone to participate fully. Members will attempt to present their views succinctly and cooperate with the chair to ensure that everyone is given equitable time to state their ideas.
5. Members shall avoid interrupting and will listen respectfully to others.
6. Only one person will speak at a time. Members will not participate in side conversations.
7. Members are encouraged to share individual experiences, perspectives, and interests and recommend ways to achieve the council priorities within the limitations and opportunities of the legislation.
8. Members shall work together to identify where there is common ground and where there are key differences between perspectives.

9. Members are encouraged to inform and solicit the opinions of others in the rare disease community and organizations that are interested in the rare disease community.
10. All members take responsibility for the success of the meeting and are respectful of others' views and opinions.
11. Innovation is encouraged by listening to all ideas and creating strategies and recommendations that build on differing and common perspectives and interests.
12. Recognize that the council must operate in an open and public manner.

Discussion

The council chair may bring various agenda items to the council for discussion. The chair will inform the council members when the discussion becomes circular and will subsequently summarize the discussion sentiments. During a council discussion, members are to be mindful of waiting to speak and allowing everyone to speak. All members wishing to discuss the matter under consideration should be given the opportunity to do so.

Public Participation

From time to time, the council may elicit public participation. When the agenda calls for public participation, the council chair will call on individuals who wish to provide comments. When individuals are recognized to speak, they will have 3 minutes to speak. The council chair may adjust this time as needed.

Council Subcommittees

From time to time, the council may establish subcommittees made up of council members.

Subcommittee Membership

Subcommittee membership shall consist of an odd number of members.

No subcommittee shall have more than 15 council members.

Members within a subcommittee cannot work together outside of the official posted meeting times unless the number of members is less than the subcommittee quorum. For example, a subcommittee with five members cannot have an external meeting of 3 or more members. A subcommittee with seven members cannot have an external meeting of 4 or more.

Subcommittees may have external participants. External participants can bring expertise or information pertinent to the discussion.

External participants will not have voting rights.

Facilitation of Subcommittee Meetings

Each subcommittee shall have a chair to coordinate and lead the group. The council chair shall appoint the subcommittee chair.

Each subcommittee shall meet as directed by the subcommittee chair in collaboration with the council coordinator and the council chair.

Subcommittee Rules

Subcommittees shall meet as directed by the subcommittee chair in collaboration with the council coordinator and the council chair.

Subcommittees must follow the same open meeting law procedures as the larger council. For example, posting meeting times and agendas, taking attendance, meeting quorum, taking meeting minutes, including voting and external discussion.

Subcommittees can meet in person or virtually, but all meetings must be accessible to the public, and notices must be posted as required by open meeting law.

Subcommittees will present their discussions, activities, and votes to the full council as directed by the council chair.

Subcommittees can meet jointly to enhance coordination between the subcommittees in achieving Council priorities. Similarly, representatives from one subcommittee may be invited to participate in another subcommittee's meeting to facilitate communication and collaboration between subcommittees. No joint meeting may exceed 15 members.

Subcommittees can be disbanded if the subcommittee or larger council votes to do so.

Subcommittee Chair Responsibilities

Set a meeting time and location/virtual in collaboration with the council coordinator

Set an agenda in collaboration with the council coordinator.

Facilitate subcommittee meetings.

Take attendance roll call at subcommittee meetings to ensure a quorum. (if a quorum is not met, the meeting must be adjourned and rescheduled)

Call the meeting to order, facilitate the discussion according to the agenda, conduct a roll call vote to approve the minutes from the previous meeting, take deliberation votes by roll call as directed by the agenda, and call a vote to adjourn.

Council Coordinator Responsibilities to Subcommittees

Work collaboratively with the subcommittee chair to coordinate activities.

Set meeting date and time in collaboration with subcommittee chair. If virtual, create a link for a meeting in coordination with DPH IT Facilitator.

Coordinate with DPH IT Facilitator to ensure organized storage of all meeting notices, agendas, documents, and minutes.

Email Attorney General, Secretary of State, and Accounting and Finance Office of Public Meeting Notices as required by Open Meeting Law.

Ensure that all notices are posted as required by Open Meeting Law.

DPH IT Facilitator Responsibilities

Work collaboratively with the council coordinator to create meeting links for all council and subcommittee meetings.

Facilitate all virtual meetings ensuring the proper recording of audio, visual, and transcript files.

Shall share all recordings of audio, visual, and transcript files with the council coordinator, subcommittee chair, and council chair.

Store and maintain all records of the council and subcommittees, including meeting notices, meeting agendas, meeting minutes, meeting discussion documents, and presentations as required by open meeting law.

Financing the Work of the Council

The legislative language allows for the collection and distribution of funds in order to carry out the activities and goals of the council.

“The advisory council may accept and solicit funds, including any gifts, donations, grants or bequests or any federal funds, for any of the purposes of this section. Such funds shall be deposited in a separate account with the state treasurer, be received by the treasurer on behalf of the commonwealth, and be expended by the advisory council in accordance with the law.”