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

**STEERING COMMITTEE**

REMOTE MEETING:    Thursday, November 3, 2022, 4:00-5:00 PM

Meeting Minutes Approved 2.16.23

**Dr. Tierney Welcomed all to the meeting.**

**Quorum Roll Call**

|  |  |
| --- | --- |
| Member | Present |
| Representative Hannah Kane | - |
| Dr. Jeff Livingstone | X |
| Jenn McNary | X |
| Dr. David Miller | X |
| Michele Rhee | - |
| Dr. Ryan Thompson | X |
| Dr. Dylan Tierney | X |

**Quorum** established. Meeting was called to order at 4:02 pm.

Dr. Tierney asked if all received the minutes from the last steering committee meeting (8.25.22). All replied yes. He then asked if anyone had any edits or corrections. No one responded.

Dr. Livingstone made a motion to vote on approval of the minutes from 8.25.22

Dr. Miller made a second

Rep. Kane joined the meeting.

**Roll Call Vote to approve minutes from 8/25/22 Steering Committee**

|  |  |  |
| --- | --- | --- |
| ***Member*** | ***Approve*** | ***Don’t approve*** |
| Representative Hannah Kane | Yes |  |
| Dr. Jeff Livingstone | Yes |  |
| Jenn McNary | Yes |  |
| Dr. David Miller | Yes |  |
| Michele Rhee | - |  |
| Dr. Ryan Thompson | Yes |  |
| Dr. Dylan Tierney | yes |  |

Unanimous. Minutes approved.

Dr. Tierney reviewed the discussions from past meetings about setting the goals for the council.

He asked that the committee consider the workplan format as presented. Each priority would have goals and outcomes and very specific objectives. He asked if it was reasonable to consider at least one goal for each priority.

Priorities, as approved in prior meeting, include:

* 1. **Improving healthcare access and quality for people with rare diseases**
  2. **Establishing social supports for people impacted by rare diseases**
  3. **Strengthening the rare disease community in Massachusetts**

Dr. Tierney asked for a discussion on the topic.

* J. McNary - stated that she hopes that all goals should have attainable and measurable outcomes.
* Dr. Tierney – stated that he hoped that each goal would be developed using the SMART method. (Specific, Measurable, Attainable, Realistic, and Time-specific.
* Dr. Thompson – agreed
* Dr. Tierney asked all to look at the example work plan. As an example of a goal, we may consider figuring out the prevalence of rare diseases in Massachusetts as one of our goals. To accomplish that goal, we would have to do a lot of time-consuming activities. He asked if this is important to the committee and the committee’s work.
* Dr. Miller – suggested that we may be able to ask NORD how they estimated the rare disease prevalence and also ask what other states have done.
* Rep. Kane – stated that she felt that it would be very important to understand the prevalence of rare diseases in Massachusetts. Even though it may be time-consuming, it will set the foundation for a lot of the other work we need to do.
* J. McNary – stated that she felt that knowing the prevalence was very important. When advocating for any kind of support or resource, it would be important to know how many people may be affected.
* Dr. Thompson – Asked if we could use claims data from the Division of Insurance.

Dr. Tierney asked how many goals we should develop. He also asked if the committee felt that more than one goal could be conducted simultaneously. Stating that there was a lot to do, and then he asked the committee how they felt the work could be accomplished.

* Rep. Kane – suggested that all council members should be on at least one subcommittee. This is a working council, and all members should understand that everyone needs to contribute.
* Dr. Thompson – agreed
* J. McNary – agreed and asked if members could be on more than one committee if they had time.
* Dr. Tierney – stated that, yes, the committee had decided that people could be on more than one committee.
* Rep. Kane – Suggested that maybe the work should be split between committees. Some of the work will require research expertise, but others may not need specific research background. For example, collecting information about the rare disease advocacy groups in Massachusetts wouldn’t take a research background to do that.
* Dr. Livingstone – Agreed that we should work on goals simultaneously.

Dr. Tierney asked the group how they wanted to address the many topics brought up in the last full council meeting. For example, one discussion was about creating a Bill of Rights for those with rare diseases. Although that does not address any specific legislative charge, it seemed important to the committee.

* Rep. Kane – stated that we should try to complete the legislative charges as a priority, and if there were additional resources or time, we could work on some of the other topics that people were interested in, like, the Patient’s Bill of Rights.
* J. McNary – asked if we could utilize people outside of the committee to help get the work done.
* Dr. Tierney – responded by stating that yes, the committees to seek outside help, and if they wanted to come to a meeting for discussion, they could as long as they were on the agenda.
* Rep. Kane – stated that the legislature put specific charges in the bill, and we should work toward meeting those charges. Although it would be time-consuming, it was important foundational work. The work to determine prevalence would help to drive some of the other patient-specific goals and activities. She felt that this foundational work was very important.
* Dr. Livingstone – agreed.
* Dr. Thompson – agreed. He also said we needed to remember that we were an advisory council. It wasn’t our responsibility to create but to advise.
* Rep. Kane – stated that one activity that may be done simultaneously could be to monitor bills and proposed legislation that may affect the rare disease community. If we know about those bills and legislation, and we know the prevalence, we may be able to advocate for or against whatever is being proposed. She reiterated that data is needed to defend the legislation.

Dr. Tierney asked if the group felt that each priority should have at least one goal to start.

* Rep. Kane – I agree that we should have at least one goal per priority, and we should just realize that this foundational work is needed for a lot of the other work to be done.
* Dr. Tierney – As we develop timelines for each goal, we will have a better idea of the work and what can get done in that timeframe. Dr. Tierney also stated that there were only three people on the research subcommittee, and if we wanted the goal of determining prevalence to be a priority, how would we get it done?
* Dr. Miller – suggested that all members should be on a subcommittee, and if they don’t volunteer, Dr. Tierney, as chair, should assign them.
* Dr. Thompson – agreed.
* Rep. Kane – suggested that people might sign up if they knew what they were working on. It may make sense to ask people to sign up based on the goal instead of a subcommittee.
* Dr. Miller – suggested that we call the groups workgroups instead of subcommittees. This may resonate with people that it will require some work.
* Dr. Thompson – agreed that he like referring to the groups as workgroups.

Dr. Tierney asked the group if it made sense to reach out to all members with the three goals proposed and ask which one they would like to work on.

* Rep. Kane – agreed that this might help solicit volunteers to work on the goals.

Dr. Tierney asked if we all agreed to start on the following three goals.

**Strategic Priority 1**

***Improve healthcare access and quality of care for people with rare diseases.***

**GOAL 1**

Determine the prevalence of rare diseases in Massachusetts.

**Strategic Priority 2**

***Advocate for and improve access to social supports and services for people impacted by rare diseases.***

**GOAL 1**

Develop a profile of rare disease social supports and services in Massachusetts.

**Strategic Priority 3**

***Foster communication and collaboration to empower the rare disease community in Massachusetts.***

**GOAL 1**

Develop a profile of rare disease expert individuals, community-based organizations, voluntary organizations, healthcare providers, and any other public or private organizations with interest in rare diseases in Massachusetts.

**Dr. Tierney stated that it was 5:00 pm. Did the committee have any other thoughts or comments, or was there a motion to Adjourn?**

* Rep. Kane made a motion to adjourn
* Dr. Livingstone made a second

Dr. Tierney asked if all were in favor of adjourning, after a unanimous yes.

Dr. Tierney adjourned the meeting at 5:02 pm