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

**STEERING COMMITTEE**

Approved by Steering Committee on November 3, 2022

REMOTE MEETING:    Thursday, August 25, 2022, 10:00-11:00 AM

Meeting Minutes

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

**Roll Call**

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

**Quorum** established. Meeting was called to order at 10:02 am.

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

Rep. Kane made a motion to vote on the minutes

Dr. Miller made a second

**Roll Call Vote to approve minutes from 7/14/22 Steering Committee**

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

Unanimous. Minutes approved.

Dr. Tierney reviewed the discussions from past meetings about setting the priorities for the council. He summarized the discussion and reviewed the list

* 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 about the priority language and intent.
* Dr. Miller expressed that he would like to see the council focus be narrower so that work could get done more efficiently.
* Dr. Livingstone agreed but thought that we could find a compromise.
* Dr. Thompson suggested that we include the word services in the second bullet. He also thought that 3 priorities made sense and he agreed to keep 3.
* Dr. Livingstone suggested changing the work strengthen to enhancing in the second bullet.
* Rep. Kane suggested adding the work of care to the first bullet. Improving healthcare and the quality of care for people with rare diseases.
* Rep Kane also suggested adding a descriptor under each priority to define the reason that the council identified that specific priority. The priority should be the over-arching focus but the descriptor under it will help other to understand why the council decided on that priority.
* Dr. Miller suggested using the words, identify, prioritize, and advocate in the priorities.
* M. Rhee suggested that we should include enabling access in the priorities.
* J McNary agreed
* Dr. Miller thought we should help to identify the access barriers to quality care.
* Rep Kane reminded all that we as a council will make recommendations not create. We should focus on ways to improve access to quality care for people with rare diseases. Maybe we recommend a policy change, a regulation change, or something else but we will not be creating anything. That is not the council’s charge.
* Dr. Tierney asked if the words Promote, Advocate, and Improve would be good adjectives.
* Rep Kane suggested – supports instead of promotes. She doesn’t think promote is the right word.
* J McNary stated that she lives with 2 adult children that have a rare disease. Some of her challenges and her son’s challenges could be fixed with a small policy change. She would like to see the council work on ways to remove barriers to quality care and services. She stated that she often knows that there is a service available for her sons, but she can’t access it.
* Dr. Tierney asked if this is better language:

Advocate for and improve access to social supports and services for people impacted by a rare disease.

ALL agreed that they liked that language.

* Dr. Tierney suggested moving on to bullet 3. This bullet is very broad and can cover a wide range of goals and activities. He asked for a discussion on this bullet.
* Dr. Livingstone suggested that there is a lot of overlap and synergies between many of the organizations, programs, etc in the rare disease community however they often don’t work together. Parents of children with a rare disease often follow the work of biotech and pharma and often know more than some of the doctors. We need to figure out a way to harness the knowledge and energy of these groups and let people know about them.
* J. McNary suggests that we identify all the groups that work with rare diseases and find ways for them to connect with the people and caregivers who have a rare diseases.
* Rep Kane suggested using the word foster, collaborate or coordinate in the language.

She also stated that all priorities need to link back to the legislation language.

* Dr. Tierney revised the bullet and asked for feedback.

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

* Rep Kane agreed with that language.
* Dr. Tierney wrote up the new language as discussed and asked for comments. He presented a word document so that all could review it. The word document state the council's priorities as follows:
* Improve healthcare access and quality of care for people with rare diseases
* Advocate for and improve access to social supports and services for people impacted by rare diseases
* Foster communication and collaboration to empower the rare disease community in Massachusetts
* Dr. Tierney asked if the group was ready to vote on the priorities.
* Dr. Miller made a motion to vote
* Dr. Thompson made a second

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

Unanimous vote. Motion carried and the priorities as stated will be brought to the full council in September.

Dr. Tierney stated that the next item on the agenda was the standard operating agreement draft. He asked if everyone received the revised draft that was sent yesterday.

* Dr. Livingstone asked about council membership. There were questions about terms and how many terms one could serve. He specifically asked if someone moved out of state would affect their membership.
* Rep Kane explained that the language he was referring to was in an older version. The revised version clarified that the appointing authority in the legislation would decide who served and how long they served.
* Dr. Tierney outlined the role of the council members.
* Rep. Kane agreed and summarized that the member’s responsibilities were specifically about carrying out the charges in the legislation.
* Dr. Tierney put up the revised version on the screen for all to see. This version stated that the members would serve a 3-year term until their successor was appointed. The appointing authority stated in the legislation would determine the number of terms and if there was a replacement, they would name the replacement.
* Dr Thompson stated that groups often have members that continue longer than their original term. It was good to have continuity and also good to have new members from time to time.

Dr. Tierney added language stating explicitly that members could serve consecutive terms for an indefinite period.

* Dr. Livingstone agreed. He also asked about subcommittees. He asked if subcommittees could meet together. Many of the priorities and goals will overlap with committees and thought that it would be important that committees could meet together.
* Dr. Tierney added a bullet to the subcommittee rules stating that Subcommittees could meet together.
* Dr. Tierney asked if everyone was ready to take a vote on the operating procedures as discussed.
* Dr. Miller made a motion to vote on the operating procedures
* Dr. Livingstone made a second.

**Dr. Tierney took a Roll Call Vote: Operating Procedures**

|  |  |  |  |
| --- | --- | --- | --- |
| ***Member*** | ***Approve*** | ***Don’t approve*** | ***Comments*** |
| Representative Hannah Kane | Agreed |  | By text |
| Dr. Jeff Livingstone | agreed |  |  |
| Jenn McNary | NA |  | Had to leave the meeting |
| Dr. David Miller | agreed |  |  |
| Michele Rhee | agreed |  |  |
| Dr. Ryan Thompson | agreed |  |  |
| Dr. Dylan Tierney | Agreed |  |  |

The majority voted yes so the motion carries. The operating agreement as voted will go to the full council meeting in Sept. for a full council vote.

**Dr. Tierney stated that it was 11 am was there a motion to Adjourn?**

* Dr. Miller made a motion to adjourn
* Dr. Livingstone made a second
* All in favor
* Dr. Tierney adjourned the meeting at 11:00 am