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

**STEERING COMMITTEE MINUTES**

REMOTE MEETING:    Thursday, July 14, 2022, 10:00-11:00 AM

APPROVED AUGUST 25, 2022

* **Welcome by Dr. Tierney, subcommittee chair**
* **Roll Call**

|  |  |
| --- | --- |
| Member |   |
| Representative Hannah Kane | present |
| Dr. Jeff Livingstone | present |
| Jenn McNary | present |
| Dr. David Miller | present |
| Michele Rhee | present |
| Dr. Ryan Thompson | Not present |
| Dr. Dylan Tierney | present |

* **Quorum established. Meeting called to order by Dr. Tierney at 10:03**
* **VOTE**  to approve meeting minutes from the last steering committee meeting on 5/27/22.

Rep. Kane made a suggestion to modify the notes to better reflect the work of the council. The language change suggestion is as follows:

 “The RDAC deliverable is a report to the legislature.” Should change to

 **“The RDAC is responsible for conducting a comprehensive list of deliverables as outlined in the legislative language.”**

Dr. Tierney asked for a motion to vote on the minutes with the revisions as presented by Rep. Kane. Rep. Kane made a motion to vote on the minutes as revised. Jeff Livingstone made a second.

**Dr. Tierney conducted a Roll Call Vote to approve minutes from 5/27/22 Steering Committee as presented.**

|  |  |
| --- | --- |
| ***Member*** | ***Approve*** |
| Representative Hannah Kane | X |
| Dr. Jeff Livingstone | X |
| Jenn McNary | X |
| Dr. David Miller | X |
| Michele Rhee | X |
| Dr. Ryan Thompson | Not present |
| Dr. Dylan Tierney | X |

* **Dr. Tierney presented the Mission statement draft for discussion**

**Mission Statement DRAFT**

The Massachusetts Rare Disease Advisory Council’s (MA RDAC) mission is to provide advice on rare disease research, diagnosis, treatment, and education to the Governor, the Legislature, the Department of Public Health, and the Public.

**Discussion**

J Livingstone: recommended changing the word “advice” to “guidance”

J McNary: agreed and suggested adding the word “recommendations”

Rep Kane: Agreed that both words are appropriate and should be part of the mission. She also stated that “and the Public” is not really the intent. The public is a beneficiary of the work of the council but the council doesn’t report to the public.

J McNary: suggested that it should include, improving the lives of all people affected by rare diseases. She emphasized improving the quality of life for those with rare disease.

Dr. Tierney suggested the following wording:

***“The Massachusetts Rare Disease Advisory Council’s mission is to provide guidance and recommendations on rare disease incidence and the status 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.”***

**VOTE** Rep Kane made a motion to vote on the mission statement as stated.J Livingstone seconded the motion. Dr. Tierney conducted a roll call vote.

* **Roll Call Vote**

|  |  |
| --- | --- |
| ***Member*** | ***Approve*** |
| Representative Hannah Kane | X |
| Dr. Jeff Livingstone | X |
| Jenn McNary | X |
| Dr. David Miller | X |
| Michele Rhee | X |
| Dr. Ryan Thompson | Not present |
| Dr. Dylan Tierney | X |

**Review Legislative Language:** Dr. Tierney explained that we needed to review the legislative language and assign the charges to specific subcommittees. He suggested the following subcommittees.

* **Steering**
* **Research**
* **Advocacy**
* **Fundraising**

**Discussion**

Rep Kane said she reviewed the changes and suggested each of the proposed subcommittees. (Dr. Tierney shared Rep Kane’s document)

Rep Kane presented her thoughts on subcommittee assignments according to the legislative directives. She also reminded the group that there was a 180-day report that was past due.

Her recommendations were as follows:

**Council:**

(iii) receive and consider reports and testimony from expert individuals, the department, community-based organizations, voluntary health organizations, healthcare providers and other public and private organizations recognized as having expertise in rare disease care, to learn about their contributions to rare disease care and possibilities for the improvement of rare disease care in the commonwealth;

**Steering:**

(i) coordinate the performance of the rare disease advisory council's duties with those of other rare disease advisory bodies, community-based organizations and other public and private organizations within the state for the purpose of ensuring greater cooperation regarding the research, diagnosis and treatment of rare diseases. The coordination shall require, when appropriate: (1) disseminating the outcomes of the advisory council's research, identified best practices and policy recommendations; and (2) utilizing common research collection and dissemination procedures;

(f) On or before December 31st of each calendar year, the advisory council shall file a report with the clerks of the house of representatives and the senate and the executive office for administration and finance, which shall include, but is not limited to: (i) a summary of the current state of comprehensive rare disease plan for the commonwealth; (ii) those actions taken and progress made toward achieving implementation of the comprehensive rare disease plan; (iii) an accounting of all funds received by the council, and the source of those funds; (iv) an accounting of all funds expended by the council; and (v) to the extent practicable, an estimate of any cost savings on the part of individuals and the commonwealth that will occur upon full implementation of the comprehensive rare disease plan and accompanying programs.

SECTION 3. On or before 180 days following the effective date of this act, the rare disease advisory council shall provide a preliminary report to the governor, the department of public health and to the general court, by filing the same with the clerks of the house of representatives and the senate. The preliminary report shall include, but is not limited to, an estimate the financial, informational and other resources needed to achieve the goals and duties of the advisory council.

**Research:**

(ii) using existing publicly available records and information, undertake a statistical and qualitative examination of the prevalence and causes of rare disease to develop a profile of the social and economic burden of rare disease in the commonwealth;

(vii) research and determine the most appropriate method for the commonwealth to collect rare disease data, including a database of all rare diseases identified in the commonwealth along with known best practices for care of said diseases and such additional information concerning these cases as the advisory committee deems necessary and appropriate to conduct thorough and complete epidemiological surveys of rare diseases, subject to all applicable privacy laws and protections;

(v) determine the human impact and economic implications of early treatment of rare diseases versus delayed or inappropriate treatment of rare disease as it pertains to the quality of care, the quality of patients’ and their families lives, and the economic burdens; including insurance reimbursements, rehabilitation, hospitalization and related services on patients, families and the commonwealth;

(vi) evaluate the current system of rare disease treatment and available public resources to develop recommendations to increase rare disease survival rates, improve quality of life and prevent and control risks of co-morbidities for rare diseases, based on available scientific evidence;

**Advocacy:**

(iv) develop methods to publicize the profile of the social and economic burden of rare diseases in the commonwealth to ensure that the public and healthcare providers are sufficiently informed of the most effective strategies for recognizing and treating rare diseases;

(viii) examine the feasibility of developing a rare disease information and patient support network in the commonwealth to aid in determining any genetic or environmental contributors to rare diseases; and

(ix) develop and maintain a comprehensive rare disease plan for the commonwealth, utilizing any information and materials received or developed by the advisory council pursuant to this subsection, and which shall include information specifically directed toward the general public, state and local officials, state agencies, private organizations and associations, and businesses and industries.

**Fundraising:**

(e) The advisory council may apply for, and accept any grants of money from the federal government, private foundations, or any other source which may be available for programs related to rare diseases or to advance the mission of the advisory council.

**DISCUSSION –** Dr. Tierney asked if anyone had thoughts about this structure

J Livingstone: agreed that the subcommittee structure made sense.

M Rhee: agreed that it was important to keep it broad to begin

Rep. Kane suggested that changing the Advocacy group to Policy and Advocacy may make sense.

J McNary: Agreed. She also stated that we should figure out priorities as there is so much to do

J Livingstone: Agreed

Dr. Miller: stated that we needed to figure out what specific activities would be needed under each deliverable and have a timeline for completing it.

Rep Kane: suggested that maybe the fundraising subcommittee should be under the steering committee. She felt that fundraising should only be 1 or 2 people.

Dr. Miller: suggested that fundraising can take up a lot of time and agreed that it may only be a couple of people but that it should stay as its own subcommittee.

Rep. Kane: suggested that we needed to define how the subcommittees should operate. We should allow subcommittees to get opinions and thoughts from people outside the Council if they have the expertise to bring to the discussion. She also stated that we need to present this structure to the larger council, but we should be specific with our priorities. She suggested that we share the mission statement, legislative language, and subcommittee structure with the whole council, so they have time to review and discuss it at the next meeting.

J McNary: agreed

**Subcommittees –** Dr. Tierney asked if anyone had any additional thoughts on the subcommittee structure as presented.

Rep Kane made a request that we ask the full RDAC to consider priorities prior to the next meeting. Priorities should be achievable and impactful for people impacted by a rare disease. The priorities will be a major point of discussion for the next meeting. We discussed the idea of using break-out rooms for discussion of priorities, facilitated by steering committee members. We discussed the need to see if this complies with OML.

Dr. Tierney asked Rep Kane if she would be comfortable presenting on the need to develop priorities during the next meeting.

No one had additional thoughts or comments, so Dr. Tierney went on to the next agenda item. Meeting schedule.

Dr. Tierney suggested a meeting schedule as follows:

The full council would meet every other month beginning in July 2022.

The steering committee would meet every other month starting in August.

Other subcommittees (Policy and Advocacy, Research, Fundraising) would also meet every other month during the same month as the steering committee.

Dr. Tierney asked if anyone had any thoughts or comments about the schedule.

Rep Kane: Suggested that subcommittees could meet as much as they want.

Dr. Tierney noted that it was now a few minutes before 11. Did anyone have any additional thoughts before adjourning?

No one responded, so Dr. Tierney asked for a motion to adjourn.

Rep. Kane made a motion to adjourn.

J Livingstone made a second to the motion.

**Dr. Tierney Adjourned the meeting at 11:00 am.**