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

**Steering Committee Meeting**

Thursday, December 15, 2022

10:30 AM – 11:30 AM

**REMOTE MEETING:** https://us06web.zoom.us/j/86521092009?pwd=bjRoSUV3OEVZMnBNZ3cySlJOallOQT09

**Welcome**

* **Roll Call (Call to order if a quorum is met)**

**VOTE on approval of minutes from last Steering Committee meeting 11.3.22**

* **Review of Workgroup composition and chairs**
* **Review of the annual report draft due to the legislature on December 31, 2022.**

“Annually, not later than December 31, 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 not limited to: (i) a summary of the current state of the 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 (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.”

* **Discussion: How will we define “comprehensive rare disease plan”**
* **Review schedule for future steering committee meetings**

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| [https://us06](https://us06web.zoom.us/j/83407469310?pwd=bW1WQlp6MkVCMkhLdGpqU1VaU3FSQT09) |

**Adjourn**