

## Rare Disease Advisory Council

November 28, 2023 | 2:00-3:00pm

### Meeting Minutes

**Members present:** Lesley Bennett, Colleen Brunetti, Mary Caruso, Emily Germain-Lee, Dorian Long, Craig Miller, Miriam Miller, Michele Spencer-Manzon

**Members absent:** Jim Carson, Kevin Felice, Joanna Gell, James Rawlings, Saurabh Vaidya

#### Introductions

- The meeting began at 2:02pm
- Formal roll call, members of the committee introduced themselves and their position on the RDAC

#### Purpose of the meeting/overview

- Michele summarized the main points from the previous meeting – strategic planning, goals of the group, and beginning discussions of rare disease day
- The committee voted to approve last month's meetings

#### Public comment period

- Members of the public introduced themselves, around 14 members of the public were present

#### Updates and Previous Items

- Discuss meeting format
  - Group members would like to be in-person but there are logistical challenges
  - Leslie expressed that meeting in-person is important, and would love to continue having more hybrid meetings – two in-person per year
  - Craig suggested being deliberate with selecting certain meetings to be in-person, so that members do not have to work out logistics every month, but can still meet in person a few times a year
  - Michele suggested March 26 meeting for an in-person meeting – chairs will get information on location ASAP, will likely be JAX or Yale
    - Note: this means both Jan and Feb will be fully virtual meetings
- Rare disease day planning
  - Lesley asked about February 28<sup>th</sup> (Wednesday) versus February 29<sup>th</sup> (Thursday) for Rare Disease Day, Michele expressed a preference for the 29<sup>th</sup> because it is a rare day
    - ▣ Leslie tossed out some ideas for RDD such as a breakfast or a press conference where the RDAC talks about their work and advocacy

## Discussion of new items

- Bylaws
  - Leslie spoke about the bylaws and asked if members had comments on them – a lot of information is taken from preexisting committees
- Soliciting Funds
  - Leslie announced that the group will be soliciting funds for RDAC's operation and construction of a website
- Executive Committee
  - The executive committee will set the agenda for each RDAC meeting and set the strategic plan for the year
  - Leslie discussed forming an executive committee – could be the chairs, treasurer, secretary, and representative from the state
    - Leslie asked for comments, and if any members were interested in being treasurer or secretary
    - Secretary will be responsible for making sure everything on the website is correct
  - For secretary: Looking for someone with proofreading and editing skills
    - Colleen Brunetti mentioned that she has these skills but is low on time, needs time to consider
    - Emily Germain-Lee commented that she would be happy to look over minutes Melia compiles
  - RDAC members had a lot of questions about the website and other new items – committee members would like to take this up at the next meeting
- Subcommittees
  - Leslie: Recommended that the RDAC have three subcommittees – operations (funding and dealing with the website), education and research, legislation (potential legislation we would be seeking)
    - Members of the public can serve on subcommittees
  - Emily suggested keeping education and research separate
  - A five-member executive committee is favored – even though there will be one secretary and one treasurer, members of the RDAC and the public can help with the workload of the group overall
    - Members want to make sure there is at least one appointed member per subgroup, ideally a member of the executive committee
- Misc. Items
  - Colleen asked about the use of ambulance services within the rare disease community, Michele responded saying that the community are not that high use comparatively
  - Discussion of raising awareness of how complex the rare disease patient population is
  - Michele stated that some of the items raised would be good to include in a 2024 strategic plan

## Summarize meeting

- The group will continue work on strategic plan

- Miriam (DPH Commissioner’s designee) reminded members of the public that they may only comment during the designated public comment period, otherwise only the appointed members are allowed to contribute
- If you are interested in being secretary or treasurer, let Leslie know
- Goal is to have bylaws done by first or second week of January
  - Leslie and Michele will send out a copy of the bylaws for members to edit and give additional input on, these bylaws will not be made available to the public until they are in a final state
- No meeting in December, next meeting is end of January virtually (January 23)
  - Join Zoom Meeting  
<https://us02web.zoom.us/j/82809850276?pwd=dXZWSjgrTkY1Mkp6Yi9zQVpGd28zQT09>
  - Meeting ID: 828 0985 0276  
Passcode: 091827

### **Closing**

- The meeting adjourned at 2:58pm