

# Rare Disease Advisory Council

September 11, 2023, 3:00-4:00pm

Meeting Agenda:

<https://egov.ct.gov/PMC/Event/Details/22472>

Zoom Link:

<https://us02web.zoom.us/j/88064312509?pwd=RUNOeHY1UDAYszlrTDQ3cWYxTzIHUT09>

## Call To Order

3:02pm - Miriam: Call meeting to order

- Designee and temporary chair of the committee
- Will be electing a chair and vice chair, and discussing committee bylaws
- Excited to bring this group together (a long time coming) well before the legislative deadline

3:03pm – Deputy Commissioner Jody Terranova

- Background as a pediatrician, understands the impact rare diseases can have on children
- Excited for the work this group will do

## Introductions

3:06pm - Miriam: next steps

- Roll call style introductions as it is the first meeting
- Future meetings will just be the chairs

## Public Comment

- Kevin Friert: a little hard to hear Miriam

## Overview of the Responsibilities of the Council

- 3:21pm Miriam: sharing screen – Sec. 19a-6t
- A lot of the provisions are permissive, and thus can be changed
- What questions or recommendations do members have on this charter for the council
- SCDAA of Southern CT: is there funding available to execute these deliverables
  - Miriam: there is no state funding at the moment

## Elections – Chair and Vice Chair

- Lesley Bennett and Michele Spencer-Manzon acknowledge that there must be an official chair and vice chair, but would like to be Co-chairs/as egalitarian as possible
- Colleen Brunetti seconds Michele as Chair and Lesley as Vice Chair, no opposition heard
- No other nominations
- Michele Spencer Manzon elected as Chair, Lesley Bennett elected as Vice Chair

## Bylaws

- Lesley: Not going to reinvent the wheel, will circulate draft bylaws in the coming weeks and ask for edits/modifications
- Michele: what is the workflow, how will we be primarily communicating
  - Lesley: will be sending bylaws by email, and can meet by Zoom if we need to
- October 13 for the first draft of bylaws, October 27 for final draft
- Colleen: what platform will bylaws be on
  - Preference for google docs

- Saurabh volunteered as tech expert, says start with Google docs
- Germain Lee – is it better to do it with Gmail?
  - Michele: you have to have a gmail account
  - Germain, everyone should send their gmail to saurabh
    - [Saurabh.Vaidya2017@gmail.com](mailto:Saurabh.Vaidya2017@gmail.com)
- Miriam: everyone send their headshot, bio + gmail contact to Miriam

### Meeting Cadence

- Michele: how often we will meet, and the type of meeting we will have (in-person, hybrid, virtual)
- Lesley: Law says the group must meet 6x during the first year, and quarterly in the years after that
  - This is the minimum
- General Discussion
  - Michele's feeling is we should start monthly
  - Alison Leeds: for monthly meetings, make the weekday and time consistent
  - Craig: in favor of at least once a month meetings to get started for the first six months
    - SCDA of Southern CT seconds this
  - Lesley: every other month we have it hybrid, and the other ones be zoom meetings
  - Michele: core committee meeting as much as possible in person
  - Colleen: personally prefers in person, but wants to be cognizant for people who are taking care of high-risk individuals
  - Michele: All in-person meetings will be hybrid, some will be virtual
- Day/Time that works discussion
  - Preference for afternoons, but a lot depends on the day
  - Preference to send out a poll for scheduling
  - Michele/Lesley will send out a doodle poll with options
- Discussion of in-person meeting location
  - Potentially two main meeting hub locations so the same people don't have to drive every time

### Final Questions

- Meeting minutes?
  - Will be posted
- Where is the site for the agenda?
  - Secretary of state website for meeting agenda, members of the council will also receive the agendas directly
  - Will send around instructions for how to find agendas on the SOTs website

### Adjourn

- 3:58pm Michele called for the meeting to adjourn