

Rare Disease Advisory Council Minutes

October 24th, 2023, 2:00pm-3:00pm

Meeting Agenda:

<https://egov.ct.gov/PMC/Event/Details/22818>

In-person attendees:

- Michele Spencer-Manzon, Leslie Bennett

Zoom attendees:

- Joanna Gell, Mary Caruso, Miriam Miller, Colleen Brunetti, Saurabh Vaidya, Craig Miller, Jim Carson, Dorian Long (DSS), Emily Germain-Lee, Jim (James) Rawlings

Call to Order

- 2:11pm – meeting commenced
- Introductions of all voting members
- Michele stated the plan for this meeting is to focus on bylaws

Administrative

- Discussion of the recurring meeting times and who cannot attend
- Chairs asked if meetings should continue to be hybrid or if the council should shift to virtual
 - Craig expressed the desire to continue having an in-person meeting
- Joanna Gell and Craig Miller are open to hosting in-person meetings, Emily Germain-Lee also volunteered
 - One of these members will look into space for the fourth week of November
- Chairs plan to skip the December meeting as it is December 26
- Chairs elaborated that there will always be a virtual option for meetings, and that those hosting must have a room with zoom capacity

Discussion of a letter of support to build a UDM site in CT

- Yale is applying to be a UDM site (undiagnosed network site) and Michele will be the medical director for this, but not the PI – open it up, should the council support this endeavor
- Consensus – might be good to have a small meeting with the organizations doing stuff in this space
 - Recognizes that Nov 4 is right around the corner (grant deadline)
- Craig – given the purpose of our group, no reason not to support this
- Craig – request for the group to be able to see the grant when it is finished, Michele agrees
- Michele would like to see more collaboration between institutions doing work in the rare disease community
- Michele will send the letter around to the group

Discussion of what happened at NORD

- Leslie and Colleen went to the NORD summit in DC
- Leslie: on Sunday they met with the other RDACs across the country – we shouldn't rely on any single bylaw from other states, we should construct them ourselves, and they should have a specific plan
- Recap of ideas Leslie gathered from other RDACs:
 - Some groups start each meeting with a patient to help center the meetings
 - Massachusetts formed in 2021 – Leslie recommended looking at their annual report from last year
 - MA has three sub committees – one for advocacy, one for research, and _____
 - PA has several excellent reports, they work very closely with their legislature and the department of public health – they are looking into becoming a non-profit
 - MN – their RDAC has become an executive branch committee, it has legislators on it, they recently passed a bill that allows anyone with a rare disease to go out of network to get care for it
 - Challenges with surveying patients re: confidentiality
- Leslie asked: What do committee members want to do with this group / what subcommittees do you all want to see
- Colleen shared her takeaways from the conference
 - Very important to build relationships with your reps
 - Wants to figure out who each member has connections to
 - Surveys had trouble getting diverse responses
 - Quote that stuck with her: “decisions are made by those who show up”
 - Saw lots of interest in rare disease day by CT businesses
- Mor conference takeaways
 - A lot of interest in centering the patient voice in everything, wonderful to see as this has not always been the case
 - A lot about big tech, gene editing, and other things that have the potential to change the face of rare diseases
- Note on rare disease day – NORD is not doing it this year, Leslie has been approached by members of the CGA asking if this group wants to host a rare disease day at the state house

Steps Moving Forward

- Michele recapped the next steps for the group
- Work on strategic plan, work on getting input from rare disease community/constituent, work on writing the bylaws
 - Do we want to do all three of these steps? In which order?
- Colleen: thinks the group should hear from constituents before writing the strategic plan
- Jim Rawlings – does not want to spend two years on strategic plan like Massachusetts – believes the group should work on multiple steps in tandem
- Miriam – suggested that we should survey the group offline to determine priorities, strategic plan can be determined along the way

Closing

- Closing, communicate by email, especially for agenda items
- Meeting adjourned at 3:04pm