

# STATE OF CONNECTICUT

## DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD  
Commissioner



Ned Lamont  
Governor  
Susan Bysiewicz  
Lt. Governor

### Rare Disease Advisory Council (RDAC) Meeting

Tuesday January 23, 2024 , 2:00-3:00pm

Contact: [melia.allan@ct.gov](mailto:melia.allan@ct.gov)

#### Agenda

1. Introduction
  - a. Members should state their name and role on RDAC
2. Purpose of meeting: set up RDAC Governance, strategic plans for the next year
  - a. Summary of November 2023 meeting—focus on governance, Exec Team
  - b. Approve minutes of November meeting
3. Public comment period (5-10 minutes)
  - a. Ask for speakers or read written testimony submitted to council
4. Update on Rare Disease Day 2024 at LOB (February 28, 2024 from 8:30am-11am)
  - a. Ask members of RDAC to speak at the event
  - b. Issues to present at the event
5. Discussion of Bylaws/Governance
  - a. Review rough draft of bylaws
  - b. Executive committee nominations
  - c. If necessary, formal vote on bylaws and executive committee nominations
6. Discuss ideas for potential RDAC legislation for 2024 CGA session, including:
  - a. Funding for RDAC administrative assistant position
  - b. Recommendations from RDAC members
  - c. Rapid Whole Genome Sequencing (WGS) for critically ill children
7. Summarize meeting, discuss ideas for next meeting
8. Closing: Motion to end the meeting

#### Meeting Information:

<https://us02web.zoom.us/j/82809850276?pwd=dXZWSjgrTkY1Mkp6Yi9zQVpGd28zQT09>

Meeting ID: 828 0985 0276

Passcode: 091827