

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 February 27, 2024 , 2:00-3:00pm

Contact: melia.allan@ct.gov

Agenda

1. Introduction
 - a. Members should state their name and role on RDAC
2. Purpose of meeting
 - a. Focus Governance and operational/strategic plans for the next year
3. Summary of January meeting
 - a. Bylaws, Exec Team, & approve January meeting minutes
4. Public comment period
5. Update on Rare Disease Day 2024 at LOB (February 28, 2024 from 8:30am-11am)
6. Connecticut Rare Disease Forum--JAX Labs March 7, 2024
7. Legislative Update--SB 175; discussion on bills of interest to RDAC members
8. Bylaw/Governance Overview and discussion of meetings with CGA members, PHC, state agencies
9. Next meeting--discussion concerning format for "in person" meetings
10. Summarize meeting & discuss ideas for next meeting
11. Closing: Formal motion to end the meeting

Meeting Information:

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

Meeting ID: 828 0985 0276

Passcode: 091827