

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Rare Disease Advisory Council

March 26, 2024 | 2:00-3:00pm

Contact: melia.allan@ct.gov

Agenda

1. Introduction
 - a. Members should state their name and role on RDAC
 - b. Purpose of meeting: focus on Governance and legislative issues this session
 - c. Summary of February meeting
 - d. Bylaws, Exec Team, & approve minutes
2. Public comment period
 - a. Ask for speakers or read written testimony submitted to council
3. Update on Rare Disease Day 2024 at LOB
4. March 7 JAX Labs Connecticut Rare Disease Forum
5. Report: Michele, Craig, Joanna
6. Legislative Update: Bills we are following/testifying for
 - a. HB 5367: Medicaid coverage rWGS critically ill infants
 - b. SB 206: Katie Beckett waiver expansion
 - c. SB175: Funding for RDAC
 - d. SB 307: Medicaid coverage of Biomarker testing
7. RDAC Bylaws update:
 - a. Recommendations on Version 2
8. New Business
 - a. Issues that members would like to address such as waivers
9. First Public "in-person" meeting update
10. Closing: Motion to end meeting

Meeting Information:

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

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Meeting ID: 828 0985 0276

Passcode: 091827

One tap mobile

+13092053325,,82809850276#,,,,*091827# US

Dial by your location

- +1 646 558 8656 US (New York)