

# STATE OF CONNECTICUT

## DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD  
Commissioner



Ned Lamont  
Governor  
Susan Bysiewicz  
Lt. Governor

### Rare Disease Advisory Council May 28, 2024 | 1:00-3:00pm

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## Agenda

1. Introduction
  - Members should state their name and role on RDAC
2. Purpose of Meeting
  - Receive input from the public (1-2pm) on rare disease issues/challenges
  - Formal RDAC meeting (2-3pm) to discuss bylaws, DSS waivers program, legislation, and new business
3. Summary of April Meeting; Approve Minutes
4. Public Comment Session (1-2pm)
  - a. Call speakers or read written testimony submitted to council

*Formal RDAC meeting begins (2-3pm)—public invited to attend*

5. Roll call of members present
6. DSS/Medicaid Waiver discussion (DSS personnel)
7. Legislative Update
8. Bylaws Update
9. New Business: Survey, Event Calendar, Social Media
10. Closing

## Meeting Information

In-person location:

**The Jackson Laboratory Genomic Medicine**  
**10 Discovery Dr, Farmington, CT 06032**

Virtual:

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

Meeting ID: 828 0985 0276      Passcode: 091827

Dial by your location

- +1 646 558 8656 US (New York)