

# 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

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

## Agenda

1. Introduction
  - Members should state their name and role on RDAC
- Purpose of the meeting (1-2pm)
  - Receive Input from the Public (1-2pm) on issues important to the CT Rare Disease Community
2. Public Comment Session (1-2pm)
  - Ask for speakers or read written testimony submitted to council
  - Each speaker limited to a maximum of 3 minutes
  - Speakers are asked to state name, city of residence, rare disease, and topic

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

3. Roll call of members present
4. Purpose of the meeting (2-3pm)
  - Review the minutes from May meeting, discuss Bylaws, Legislative update, discuss new business and deferred issues from last meeting
5. Minutes from May meeting—discussion and vote (if quorum present)
6. Review & vote on bylaws-- subcommittee; Craig, Colleen, Lesley
7. Legislative Update & Information session:
  - PA 24-130: Medicaid coverage rWGS infants & Katie Beckett workgroup update
  - Discussion of Prescription Drug Advisory Boards (SB 8)
8. Rare Disease Survey Draft, Annual Report, & New Business
9. Rare Disease Event Calendar
10. Social Media-Awareness Update
11. Closing: Motion to end meeting (3pm)

## Meeting Information

*In-person location:*

**Connecticut State Legislative Office Building (LOB)  
300 Capitol Ave, Hearing Room 1B  
Hartford, CT 06106**

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*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)