

# STATE OF CONNECTICUT

## DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD  
Commissioner



Ned Lamont  
Governor  
Susan Bysiewicz  
Lt. Governor

### Rare Disease Advisory Council

January 28, 2025 | 2:00-3:00pm

Note: Meeting to be conducted solely through the use of electronic equipment

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

#### Agenda

1. Member Introduction
2. Summary of December 10 Meeting & Public Hearing
  - a. Annual Report
  - b. Legislative Issues for 2025 CGA session
3. Purpose of today's meeting
  - a. Update on 2025 Legislative Priorities
  - b. Discuss Plans for RDD2025
4. Public Comment
5. Prescription Drug Task Force Update
6. Katie Beckett Waiver Update
7. "RARE" Programs at Hospital for Special Care (HFSC)
8. Yale Undiagnosed Diseases Network (UDN) Site Update
9. Advocacy Committee Business
  - a. Members: including members from public
  - b. 2025 RDAC Legislative Issues
  - c. Set Meeting Schedule
10. Awareness Committee Business
  - a. Membership
  - b. Discuss Rare Disease Day 2025 & Agenda
  - c. Set Meetings/Agenda for Committee
11. Closing

#### Meeting Information:

<https://us02web.zoom.us/j/81597571463?pwd=5saasW2M2Gim6nKQh9epJ70A5rgOZ3.1>

Meeting ID: 815 9757 1463

Passcode: 001663