

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH



Manisha Juthani, MD
Commissioner

Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Rare Disease Advisory Council

March 25, 2025 | 2:00-3:00pm

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

Contact: melia.allan@ct.gov

Agenda

- I. Member Introductions
- II. Summary of February Meeting & Rare Disease Day event
 - a. Meeting recap
 - b. RDD2025 recap
- III. Purpose of Today's Meeting
 - a. Legislative priorities during 2025 CGA session
 - b. Intellectual Disability voice--set up meeting HSC and DDS
 - c. Awareness & Advocacy Committee setup--meetings recruit new members
- IV. Public Comment
- V. Undiagnosed Diseases Network (UDN) Update
- VI. Sickle Cell Update--DSS Application (3/6) & HB 1473
- VII. Advocacy Committee Update: Legislative Priorities & Testimony:
 - a. Public Health: Emergency protocol and funding legislation
 - b. Human Services: Katie Beckett and ID/Autism, prescription drug legislation
 - c. Aging: Insurance coverage of biomarker testing
 - d. Education: 504 plan protection
 - e. Other legislation RDAC members are following
 - f. New members, meetings (virtual), push for bill passage
- VIII. Awareness Committee Update
 - a. Mapping project
 - b. Events
 - c. Education projects
 - d. New Members & meetings
- IX. New Business
 - a. Recommendations for topics for next meeting
- X. Close

Meeting Information:

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

Meeting ID: 815 9757 1463

Passcode: 001663