

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Rare Disease Advisory Council April 23, 2024 | 1:00-3:00pm

Contact: melia.allan@ct.gov

Agenda

- 1. Introduction**
 - a. Members should state their name and role on RDAC
- 2. Purpose of meeting**
 - a. Receive Input from the Public (1-2pm) on issues important to the CT rare disease community; RDAC discussion (2-3pm) of Bylaws, Katie Beckett Waiver Program; Rare Disease Survey; and new business;
- 3. Summary of February meeting**
 - a. Bylaws, Rare Disease Issues, In-person meetings; approve minutes
- 4. Public Comment Session (1-2pm)**
 - a. Call for speakers or read written testimony submitted to council

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

- 5. Update on Bylaws**
 - a. Bylaws subcommittee; Craig, Colleen, Lesley
- 6. Legislative Update:**
 - a. HB 5367: Medicaid coverage rWGS infants
 - b. SB 206: Katie Beckett waiver expansion
 - c. SB 175: Funding for RDAC
- 7. Katie Beckett Waiver: Overview by DSS**
- 8. Rare Disease Survey Draft**
- 9. New Business:**
 - a. Rare Disease Event Calendar
 - b. Social Media-Awareness Update
- 10. Closing: Motion to end meeting**

Meeting Information:

In person:

Sterling Hall of Medicine, Room I-304
333 Cedar Street, New Haven, CT

Virtual:

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

Meeting ID: 828 0985 0276

Passcode: 091827

Dial by your location

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