

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Rare Disease Advisory Council

July 23, 2024 | 2:00-3:00pm

Contact: melia.allan@ct.gov

Agenda

1. Introduction
2. Purpose of July Meeting
 - Health policy awareness & legislative update: PIPC presentation, (??Colleen Advocacy)
 - Exec team nominations, discussion, & election
 - Finish old business deferred from last meeting: Rare Survey, Annual Report
 - Discuss New business: Rare Calendar, ideas for funding RDAC activities
3. Summary of June Meeting & Minutes
4. Public Comment
 - Ask for speakers or read written testimony submitted to council
5. Health Policy Awareness
 - Partnership to Improve Patient Care (PIPC) presentation: patient-centered care and policies or AI tools that can adversely affect rare disease patients
6. Legislative Update
 - Katie Beckett Task Force, rWGS press conference, RDAC funding suggestion
 - Advocacy presentation by Colleen Brunetti
7. RDAC Structure Discussion
 - Executive Team: nominations, discussion, and election
 - Standing Committees: discussion
8. Old Business: Annual report
9. New Business: Calendar and issues/topics/locations for September and October meetings
10. Closing

Meeting Information:

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

Meeting ID: 828 0985 0276

Passcode: 091827