

## Rare Disease Advisory Council

April 22, 2025 | 2:00-3:00pm

### Meeting Minutes

**Members present:** Lesley Bennett, Emily Germain-Lee, Craig Miller, Michele Spencer-Manzon, Jim Carson, Dorian Long, Colleen Brunetti, Kevin Felice, Adrienne Manning.

**Members absent:** James Rawlings, Joanna Gell, Mary Caruso, Saurabh Vaidya.

#### Introduction

- Michele Spencer-Manzon called the meeting to order at 2:02pm.
- Members introduced themselves and stated their role on the RDAC.
- Craig Miller motioned to approve the March 25 minutes; Lesley Bennett seconded. The minutes passed without discussion.

#### Legislative Update: Bills RDAC is following and actions needed

- Lesley gave an update on several bills that the RDAC is following.
  - HB 6919: Newborn screening for DMD
    - DMD was not added to the RUSP
    - Bill will probably be held up in appropriations, given the funding concerns.
  - HB 6920: Emergency protocols for rare disease patients
    - Has a calendar number and is waiting to be called to the floor
    - No fiscal note on this bill: high priority for RDAC advocates
    - Lesley shared concern about emergency department care being run by independent contractors
  - HB 6978: RDAC funding
    - No fiscal note on this bill as a whole; it is likely to pass
  - HB 7103: Expanding the Katie Beckett waiver
    - Fiscal note is over \$300,000, so the costly portions of the bill will likely be put on hold.
  - HB 7108: Intellectual disabilities and autism bill
    - Part of this bill may go through
  - SB 1473: Sickle cell gene therapy
    - RDAC advocates are supporting this bill, because it opens the door for other cell and gene therapies in the future
  - SB 11: Prescription drug task force, prescription drug advisory council
    - Lesley is watching this bill
  - 7219: Protection of 504 plans in the Education Committee
  - 6771 and 6895: Biomarker testing
    - RDAC members were asked to support 6771 by the American Cancer Society, and to oppose 6895, because the bill imposes a time limit on testing.

- Lesley encouraged RDAC advocates to pick out a few bills and reach out to their elected officials about them.

### **Awareness Update**

- Colleen Brunetti reached out to interested individuals in the Awareness Committee to set up an initial meeting.
- She shared the committee's goal of raising awareness by mapping rare diseases across the state.
- Lesley shared two upcoming events:
  - Denise D'Ascenzo Walk to Fight Rare Diseases, Lesley and Mary will be present.
    - <https://thedenisefoundation.com/walk-to-fight-rare-diseases>
  - Connecticut Rare Action Network has a family picnic on May 10 at Winding Trails in Farmington, from 1-4pm.

### **Member terms: 1/2 up in September 2025**

- Half of the RDAC members' terms will be up in September – Lesley asked members to think about whether they want to serve another two-year term.

### **Meeting calendar for July to December 2025**

- Michele Spencer-Manzon helped facilitate a discussion on the meeting schedule for the second half of the year.
- Lesley suggested three in-person meetings in the second half of the year.
- Proposed schedule, generally on the fourth Tuesday of the month:
  - May 27, 2:00pm (remote)
  - June 24, 2:00pm (remote)
  - July 22, 2:00pm (remote)
  - August 26, 2:00pm (in-person)
  - September 23, 2:00pm (in-person)
  - October 28, 2:00pm (in-person)
  - \*December 9, 2:00pm (remote) \*combined Nov/Dec meeting.
- Themes the RDAC wants to explore in upcoming meetings: research and business in Connecticut, healthcare/academics, patient community.

### **Closing**

- The meeting adjourned at 2:55pm.
- The next meeting is scheduled for May 27, from 2:00-3:00pm.