

## Rare Disease Advisory Council

August 27, 2024 | 2:00-3:00pm

### Meeting Minutes

**Members present:** Lesley Bennett, Jim Carson, Kevin Felice, Joanna Gell, Emily Germain Lee, Adrienne Manning, Craig Miller, Michele Spencer-Manzon, Saurabh Vaidya

**Members absent:** Colleen Brunetti, Mary Caruso, Dorian Long, James Rawlings

#### Introduction

- Lesley Bennett called the meeting to order at 2:03pm.
- Members of the RDAC introduced themselves and stated their role on the RDAC.
- Saurabh Vaidya motioned to approve the July minutes; Kevin Felice seconded. The meeting minutes passed without revisions.

#### Executive Committee Selection

- Emily Germain Lee put the names of the individuals interested in being the patient representative in a hat. James Rawlings was selected as the patient representative.
- Craig Miller was selected as the healthcare representative.
- Lesley called for a motion to accept the two representatives on the executive committee. Michele motioned; Joanna seconded. All members present voted in favor of these nominations.

#### Public Comment

- Jennifer Ianuzzi, president and co-founder of Smith-Magenis Syndrome (SMS) Research Foundation, spoke about her experiences caring for her daughter with SMS..
  - She has had difficulties navigating the DDS waivers, and generally utilizing supports from DDS for her daughter, as well as other individuals with rare genetic syndromes.
  - Although her daughter qualifies for a behavioral support program, there is a shortage of people who can come out and assist in the home.
- Kevin Freiart, board member for Rare New England promoted their annual conference on October 19.
  - Information can be found here: <https://www.rarenewengland.org/rne-annual-conference-1>

#### Department of Developmental Services (DDS) presentation on waivers, eligibility, and IDD definition

- Krista Ostaszewski from DDS presented on how DDS as an agency works, their waivers, and eligibility.
- The definition of intellectual disability is articulated in statute, it is in CGS Section 1-1g.
  - DDS then looks at intelligence cognitive test results. Individual performance must be more than two standard deviations below the mean for the Full Scale IQ (FSIQ) Score.

- They also conduct tests of adaptive behavior, to document these deficits.
- She explained that once a person is found eligible, that person is assessed for DDS supports and services, to determine the best way to support each person where they are.
- DDS waiver supports are not an entitlement and are therefore subject to available appropriations.
- Three waivers:
  - Comprehensive Supports Waiver (Comp)
  - Individual and Family Support Waiver (IFS)
  - Employment and Day Support Waiver (EDS)
- Making changes to a waiver takes time and is complex – there is a requirement to hold a 30-day public comment period, as well as a public hearing with the state legislature before submission to CMS for review and approval.
- For additional questions, reach out to [Krista.Ostaszewski@ct.gov](mailto:Krista.Ostaszewski@ct.gov)

### **Discuss Annual Report Due in September**

- Lesley asked for volunteers to work on the preliminary annual report due in September.
- Joanna and Craig volunteered to help draft the report.

### **Legislative Update**

- The group discussed the need to speak to legislators about expanding state waivers to cover more rare disease patients, and hopefully raise legislation in January 2025.
- Michele asked when the council members should anticipate being at the LOB to speak to legislators and advocate for their causes. Lesley did not have a specific date but indicated that since this session is the long session from January through June, they would likely be the most active in January, when bills are being raised at the beginning of session.

### **New Business**

- Lesley recommended making the September meeting virtual, as she was unable to secure an in-person location. The October meeting will be held at Yale, and the December meeting will be held in person.

### **Closing**

- The meeting adjourned at 3:00pm.