

Rare Disease Advisory Council

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

Meeting Minutes

Members present: Colleen Brunetti, Adrienne Manning, Lesley Bennett, Jim Carson, Mary Caruso, Saurabh Vaidya, Dorian Long, Emily Germain-Lee, Kevin Felice, Joanna Gell, James Rawlings.

Members absent: Michele Spencer-Manzon and Craig Miller.

Others: Thayer Roberts, Wayne Cook, Rachel O'Grady, Ben Chandhok.

Introduction

- Lesley Bennett called the meeting to order at 2:01pm.
- Members of the RDAC introduced themselves and their role on the RDAC.
- Lesley summarized the purpose of the meeting.

Summary of June Meeting & Minutes

- Lesley recapped the June meeting, mentioning that the RDAC heard from adult patients and the issues they are facing and that the group voted on the bylaws and discussed the executive committee format. Lesley asked members to vote on the draft minutes from June.
- Colleen Brunetti motioned to approve the June minutes; Dr. Kevin Felice seconded; the minutes passed without discussion.

Public Comment

- Rachel O'Grady presented on her current struggles as a rare patient.
 - Rachel highlighted that she was supposed to receive a necessary surgery on Friday, but her insurance company denied coverage, after previously pre-authorizing the surgery. She is currently appealing to the Office of the Healthcare Advocate, but this does not provide short-term help. Rachel would like to work with the RDAC and any elected officials to look into drafting legislation to protect rare patients from predatory insurance practices.

Health Policy Awareness Presentation

- Lesley introduced Thayer Roberts from the Partnership to Improve Patient Care (PIPC) to present on patient-centered care and policies or AI tools that can adversely affect rare disease patients.
 - The Partnership to Improve Patient Care is a coalition of patient and disability advocacy organizations, focused on patient centricity within the healthcare system, and ensuring that patients and people with disabilities are being kept at the forefront of healthcare decisions. The founder is the original author of the Americans with Disabilities Act.

- Thayer presented on QALYs, or Quality-adjusted life years, a metric used to measure a person's health.
 - QALY scores generally range from 0 to 1, where one is perfect health, and 0 is death. QALYs systematically undervalue treatments for people with disabling conditions or rare diseases, as the patient will never get back to a "1" on this scale, and the QALY scale is a metric developed to do a generalized cost-effective analysis.
- Thayer spoke about other states' use of these types of metrics, in light of the prescription drug bill introduced in CT's past legislative session. Oregon, Washington, Colorado, Minnesota, and Maryland have established Prescription Drug Affordability Boards, and the language to bar the use of QALYs falls short.

Legislative Updates

- Lesley updated the group on the Katie Beckett Waiver taskforce – both Lesley and Emily Germain-Lee have been appointed to the taskforce, which is set to start meeting in August.
- There was a recent press conference for rapid whole genome sequencing at UConn; Sen. Anwar was present, and he acknowledged the RDAC's work.
- Lesley spoke with Miriam at DPH, and she suggested a two-pronged approach to getting funding: DPH will submit a legislative proposal on their end, and the CGA will also raise a bill
- DDS will be coming to the meeting next month to discuss their waivers and eligibility criteria, along with their new definition of intellectual and developmental disabilities.
 - DDS has only added 225 rare disorders to their list so far.
- Lesley spoke about the Council's annual report, which is due in September. With regards to getting an extension, Sen. Anwar recommended that the group submit a part one of their report in September but send the chairs of the Public Health Committee a letter to defer their report until December 2024, where the RDAC can provide more information.

Advocacy Presentation: Colleen Brunetti

- Colleen gave her background on how she got into rare disease advocacy work, and shared advice on being an advocate.
- She shared that the advocacy around her disease is therapeutic, and gave the following tips:
 - Raise issues that are important to you and keep your eyes on the topic at hand that the legislature is already working on and add your voice to that.
 - Always be aware of the activity that the legislators are doing and thank them for it and tell them about your own story.
 - You must have a thick skin, because people will leave negative comments.
 - Although polarization has made the advocacy scene seem red or blue, a lot of people are still reaching across the aisle to find common ground: rare disease advocacy is an issue that is supported by both sides of the aisle.
 - Remember that advocacy is a marathon, not a sprint.
 - Think outside the box about who has a stake in your community.
- Takeaway: your voice matters more than you might realize.

RDAC Structure Discussion

- The group had a discussion on the structure of the Executive Committee, centering around the patient and healthcare representatives that will serve on the committee.
- Lesley announced the members who were interested in being on the executive committee representing the patient advocacy and healthcare advocate
 - Patient reps: Colleen Brunetti, Mary Caruso, James Rawlings, and Saurabh Vaidya
 - Healthcare reps: Kevin Felice, Craig Miller, and Joanna Gell
- Given that everyone is well qualified, the group agreed that it would be difficult to select a member out of those who have expressed interest
- Colleen brought up that the skillset a member brings to the executive committee could also be important, in addition to the healthcare/patient representative.
- Lesley encouraged members to send their ideas to her on how to handle the joining of the executive committee.
- Colleen made a motion to decide how the Executive Committee is chosen (pull names out of a hat or use an interview process); Mary seconded the motion.
 - Vote tally:

Choose EC names from a hat	Use an interview process	Abstain
1. Mary Caruso 2. Colleen Brunetti 3. Emily Germain-Lee 4. Saurabh Vaidya 5. Lesley Bennett	1. James Rawlings	1. Jim Carson 2. Adrienne Manning 3. Dorian Long

Closing

- Dorian Long motioned to end the meeting; Saurabh Vaidya seconded.
- The meeting adjourned at 3:11pm.