

## **Rare Disease Advisory Council**

**July 22, 2025 | 2:00-3:00pm**

### **Meeting Minutes**

**Members present:** Lesley Bennett, Jim Carson, Mary Caruso, Joanna Gell, Emily Germain-Lee, Dorian Long, Michele Spencer Manzon, Gary Smart (SCDAA representative).

**Members absent:** Colleen Brunetti, Kevin Felice, Adrienne Manning, Craig Miller, Saurabh Vaidya.

#### **Introduction**

- Michele Spencer Manzon called the meeting to order at 2:03pm.
- RDAC members introduced themselves and stated their role on the Council.
- Emily Germain-Lee motioned to approve the minutes from June 24 and Mary Caruso seconded; the June minutes approved without discussion.
- Michele reviewed the purpose of today's meeting.

#### **Discussion on Coverage of OTC Medications by HUSKY**

- Michele raised concerns that starting July 1, HUSKY is no longer covering over the counter (OTC) medications over \$100. These are essential for patients with inborn errors of metabolism and other rare diseases, including the urea cycle disorder community.
- Michele is hoping to get a community speaker to discuss this topic further at the RDAC meetings, but she has experienced difficulties trying to get people to call her back to discuss the issue.
- Lesley recommended reaching out to Senator Anwar and setting up a meeting with the Department of Social Services (DSS).
  - Dorian offered to bring the issue back to DSS to identify an appropriate contact for the group to connect with.
- Mary Caruso shared her experience with high costs of supplements for Friedrich's Ataxia and the need for broader discussions on coverage for rare disease patients.

#### **Subcommittee Updates, Discuss Guidelines for Subcommittees**

##### *Advocacy Committee Update*

- Mary updated the group on the Advocacy Committee, which now has around 10 members. The first meeting will be held on August 11<sup>th</sup> or 12<sup>th</sup>. They plan on seeking guidance from legislators on best practices.
- From last session, Lesley highlighted two outstanding issues: Exceptions or modified EMS protocols for rare disease patients and a conditional or compassionate waiver for those born with a severe rare disease.
  - Melia will bring the EMS question back to DPH to get more information and start a conversation.

##### *Awareness Committee*

- As Colleen was not present, Lesley let the group know that the project is progressing, and they will continue to update the full group at future meetings.

#### **New Business: Undiagnosed Diseases Network (UDN) Advisory Board**

- Maria Jose (MJ) Romero spoke about Yale's Undiagnosed Diseases Network (UDN), and their creation of a Genetics Community Advisory Board (CAB) to ensure that advances in genetic research and care are connected to the needs of patient communities.
- The Board meets quarterly, with its second meeting scheduled for September 2025. MJ is seeking volunteers for patient advocates to serve on the Board.
  - Members can reach out to [undiagnosed@yale.edu](mailto:undiagnosed@yale.edu) with any questions.

#### **RDAC In-Person Meeting Update: August, September, October**

- The September meeting is set to be hosted at UConn on September 30, from 1:00-3:00pm. Emily will share directions on how to access the location ahead of time.
- The October meeting is set for Boehringer Ingelheim in Ridgefield, CT.
- Lesley motioned to host the August 26 meeting virtually and move the December meeting to an in-person hybrid modality and Mary Caruso seconded. All members present voted in favor of this motion.

#### **Member Terms: Members need to check with their appointing authority**

- Lesley reminded the group on which members have two-year versus three-year terms.
- Lesley will ask Senator Somers to appoint Gary Smart as the interim representation for SCDA and for the next term as well.
- Lesley will connect with members who are not present on whether they would like to be re-appointed to a new term.

#### **New Business: Topics for Next Meeting**

- For the NORD conference in October, the chairs of the RDAC, executive team members, or committee heads are invited to attend. Lesley needs to get information back to NORD by August 1.

#### **Closing**

- Michele motioned and Lesley seconded. The meeting adjourned at 2:55pm.